

## MINUTES OF THE SENATE WAYS AND MEANS COMMITTEE

The meeting was called to order by Chairman Stephen Morris at 10:35 a.m. on March 8, 2004, in Room 123-S of the Capitol.

All members were present.

### Committee staff present:

Alan Conroy, Director, Kansas Legislative Research Department  
J. G. Scott, Chief Fiscal Analyst, Kansas Legislative Research Department  
Michele Alishahi, Kansas Legislative Research Department  
Amy Deckard, Kansas Legislative Research Department  
Audrey Dunkel, Kansas Legislative Research Department  
Susan Kannarr, Kansas Legislative Research Department  
Becky Krahl, Kansas Legislative Research Department  
Amy Vanhouse, Kansas Legislative Research Department  
Norman Furse, Revisor of Statutes  
Jill Wolters, Senior Assistant, Revisor of Statutes  
Judy Bromich, Administrative Analyst  
Mary Shaw, Committee Secretary

### Conferees appearing before the committee:

Jane Rhys, Ph.D., Executive Director, Kansas Council on Developmental Disabilities  
Gina McDonald, President and CEO, Kansas Association of Centers for Independent Living  
Kathy Lobb, representing the Self-Advocate Coalition of Kansas  
Rocky Nichols, Executive Director, Kansas Advocacy Protective Services, Inc.  
Stephanie Wilson, Senior Administrator, Community Living Opportunities  
Laura Howard, Deputy Secretary, Division of Health Care Policy, Kansas Department of Social and Rehabilitation Services  
Tom Laing, Executive Director, InterHab  
Darla Nelson-Metzger, Employee of Families Together, Inc., (written)  
Sheriff Lynn C. Myers, Johnson County Sheriff's Office, Olathe, Kansas  
Judy Mohler, General Counsel/Legislative Services Director, Kansas Assn. Counties (written)  
Ken Grotewiel, Assistant Director, Kansas Water Office

### Others attending:

See Attached List.

## Bill Introductions

Senator Downey moved, with a second by Senator Helgerson, to introduce a bill concerning water; relating to water rights (3rs2056). Motion carried on a voice vote.

Senator Helgerson moved, with a second by Senator Downey, to introduce a bill concerning the Kansas business health policy partnership; relating to duties, expenditures and creation of a fund (3rs2067). Motion carried on a voice vote.

Chairman Morris continued the public hearing on:

### SB 531--Developmental disabilities institutions closure commission

Chairman Morris welcomed the following conferees testifying in support of **SB 531**:

Jane Rhys, Ph. D., Executive Director, Kansas Council on Developmental Disabilities (Attachment 1). Dr. Rhys distributed the following information:

- Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators (Attachment 2).

## CONTINUATION SHEET

MINUTES OF THE SENATE WAYS AND MEANS COMMITTEE at 10:35 a.m. on March 8, 2004, in Room 123-S of the Capitol.

- De-institutionalization of People with Mental Retardation and Developmental Disabilities in the United States: Was This Good Social Policy? ([Attachment 3](#))
- Are People Better Off? Outcomes of the Closure of Winfield State Hospital ([Attachment 4](#))
- Shattering Myths about Quality of Life & Quality of Services ([Attachment 5](#))
- Mental Retardation: Let's Focus on the Real Issues ([Attachment 6](#))

Dr. Rhys explained that in August 2003 the Council voted unanimously to support closure because it benefits both the people and the system. She presented several desired outcomes of hospital closure in her written testimony.

Gina McDonald, President/CEO, Kansas Association of Centers for Independent Living ([Attachment 7](#)). Ms. McDonald explained that KACIL rises in strong support of **SB 531**. She mentioned that KACIL believes in the freedom and dignity of every individual. Ms. McDonald addressed some major challenges to de-institutionalizing services: the developmental disabilities funding system, entitlement, the waiting list and those people who consider themselves to be under served and the closure decision.

Kathy Lobb, Legislative Liaison, representing the Self-Advocate Coalition of Kansas ([Attachment 8](#)). Ms. Lobb mentioned that creating this commission is a good first step in working toward community living for all. She expressed the hope that this opportunity is taken to ensure that all Kansans can enjoy the freedom of choice and independence they deserve.

Rocky Nichols, Executive Director, Kansas Advocacy and Protective Services ([Attachment 9](#)). Mr. Nichols explained that Kansas cannot continue to run its current large-bed ICF/MRs (Intermediate Care Facilities for persons with Mental Retardation) and have effective community services. He explained that KAPS is very supportive of **SB 531**, but they would support modifying the bill. Mr. Nichols addressed several different and enhanced approaches which were detailed in his written testimony.

Stephanie Wilson, Senior Administrator, Community Living Opportunities, Inc., testified in support of **SB 531** ([Attachment 10](#)). Ms. Wilson explained that while speaking of the desire for Kansas to no longer have state institutions, there is a need to talk about the current lack of capacity within the community service system to provide for individuals remaining in the state hospitals. She noted that the issue isn't knowledge of how to provide successful services, but rather inadequate funding for providing the services.

The following conferees testified as neutral parties regarding **SB 531**:

Laura Howard, Deputy Secretary, Division of Health Care Policy, Kansas Department of Social and Rehabilitation Services ([Attachment 11](#)). Ms. Howard explained that Kansas' philosophy in serving persons with developmental disabilities is contained in the Kansas Developmental Disability Reform Act. She noted that as a result of this policy and in response to the choices people and their families have made, Kansas has significantly increased the number of persons with DD served in community integrated settings. Ms. Howard mentioned that other states which have pursued similar policies have demonstrated that, provided sufficient resources, all persons with DD can be successfully supported in the community.

In closing, Ms. Howard explained that SRS agrees that the timing is right to explore the need for and use of current institutional settings in Kansas. She also mentioned that SRS believes that if a state institution closes as a result of the bill, it can happen successfully if sufficient time is given to work with individuals and their families to assist them in the transition process, while providing needed start up funds.

Tom Laing, Executive Director, InterHab ([Attachment 12](#)). Mr. Laing mentioned that InterHab offers conditional support for the process outlined in **SB 531**. He explained that their cautionary tone in the matter is due to the far more complicated questions that **SB 531** is not designed to answer, questions that are sufficiently complex to be an almost unfair assignment for the prescribed commission: i.e., the basic questions about the service environment in the community within which an effective closure plan can be successfully implemented. As to the timing of the proposal, Mr. Laing urged the committee to think seriously about initiating the issues next year, as opposed to this year for various reasons which are stated in his written testimony.

CONTINUATION SHEET

MINUTES OF THE SENATE WAYS AND MEANS COMMITTEE at 10:35 a.m. on March 8, 2004, in Room 123-S of the Capitol.

Written testimony was submitted by Darla Nelson-Metzger, Families Together, Inc., in support of **SB 531** (Attachment 13).

Chairman Morris recognized Senator Henry Helgerson who explained that all of the comments have been very constructive. He noted that this is a very difficult process because some people lose jobs, some communities may suffer economically but ultimately the decision should be made regarding what is best for the people being served. Senator Helgerson mentioned that it is time to make the decisions to work on a gradual transitional plan of doing what is right, and right financially, for these individuals.

There being no further conferees to come before the Committee, the Chairman closed the public hearing on **SB 531**.

The Chairman opened the public hearing on:

**HB 2725--Costs of maintaining inmates in county jail, fee paid by inmate**

Staff briefed the committee on the bill.

Chairman Morris welcomed Currie Myers, Johnson County Sheriff, who testified in support of **HB 2725** (Attachment 14). Sheriff Myers explained that **HB 2725** would allow for the collection of a per diem from prisoners who have been committed to the custody of the Sheriff. He noted that the per diem accomplishes two objectives:

- the prisoner experiences the financial implications that accompany criminal behavior and that can serve as a deterrent for future criminal activity, and
- the county recoups some expenses from individuals who are directly using the services.

Written testimony was submitted by Judy Mohler, General Counsel/Legislative Services Director, Kansas Association of Counties in support of **HB 2725** (Attachment 15).

There being no further conferees to come before the committee, the Chairman closed the public hearing on **HB 2725**. The committee discussed prisoner recidivism rates.

Senator Adkins moved, with a second by Senator Schodorf, to recommend **HB 2725** favorable for passage. Motion carried on a roll call vote. Senator Kerr requested statistics on prisoner recidivism rates before **HB 2725** runs in the Senate.

Chairman Morris opened the public hearing on:

**SB 527--Establishment of water supply storage assurance fund and local water project match fund administered by the Kansas Water Office**

Staff briefed the committee on the bill.

Chairman Morris welcomed Ken Grotewiel, Assistant Director, Kansas Water Office, who testified in support of **SB 527** (Attachment 16). Mr. Grotewiel explained that **SB 527** would formalize in statute the creation of two funds which would have been authorized for several years by appropriation provisos: Water Supply Storage Assurance Fund and Local Water Project Match Fund.

There being no further conferees to come before the committee, the Chairman closed the public hearing on **SB 527**.

Senator Downey moved, with a second by Senator Bunten, to recommend **SB 527** favorable for passage. Motion carried on a roll call vote.

The meeting adjourned at 11:55 a.m. The next meeting is scheduled for March 9, 2004.

SENATE WAYS AND MEANS COMMITTEE  
GUEST LIST

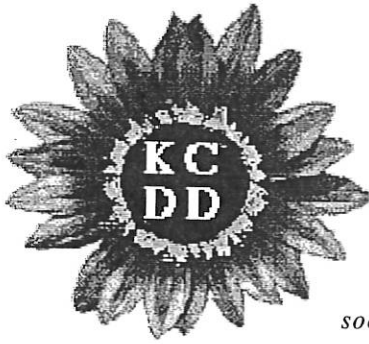
DATE March 8, 2004

NAME	REPRESENTING
Trey Allen	Sen. Salmons
Caron Dunkel	Budget
<del>Ken Myer</del>	HEW Law Team
Kenneth Leffler	Beidgel
Stephaine Wilson	CLO
Mike Hult	Ks. Gov't. Consulting
Ken Grotewiel	Kansas Water Office
Stephen Hurst	" " "
Brian Hilt	KVI
Jackie	KGP
Ladd Johnson	KLA
Doris Marchis	Little Government Relations
Lina McDonald	KACIC
Jennifer Schwartz	KACIC-ATK
Kent Weatherly	Kansas River Water Assur.
Rick Sults	STES/HCP
Tanya Dorf	SRS
Laura Howard	SRS
Wade Bowie	Citizen
Josie Terrez	516K
Rocky Nichols	KAPS
Alee Baptista	Leadership Liberal

SENATE WAYS AND MEANS COMMITTEE  
GUEST LIST

DATE March 8, 2004

NAME	REPRESENTING
Leslie Kaufman	Ks Co-op Council
Tom Linn	InterHab
Marilyn Taylor	TAR, Inc.
Judy Kohn	KAC
Danielle Nee	Johnson County
Carolyn Maddaloni	Ks St Ws Council
Kathy Job	Sack
Angie Reinken	SACK
SHERI CURRIE MYERS	JOHNSON COUNTY



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

KATHLEEN SEBELIUS, Governor  
DAVE HEDERSTEDT, Chairperson  
JANE RHYS, Ph. D., Executive Director  
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*"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"*

## **SENATE COMMITTEE ON WAYS AND MEANS**

**March 2, 2004**

Mr. Chairman, Members of the Committee, I am appearing today on behalf of the Kansas Council on Developmental Disabilities in support of Senate Bill 531, relating to state developmental disabilities institutions; creating the developmental disabilities institutions closure commission.

The Kansas Council is federally mandated and federally funded under the Developmental Disabilities Assistance and Bill of Rights Act of 2000, we receive no state funds. It is composed of individuals who are appointed by the Governor, including representatives of the major agencies who provide services for individuals with developmental disabilities. At least 60 percent of the membership is composed of individuals who are persons with developmental disabilities or their immediate relatives. Our mission is to advocate for individuals with developmental disabilities (DD) to receive adequate supports to make choices about where they live, work, and learn.

Since I last met with you I have obtained a copy of *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003* from the Research and Training Center on Community Living at the University of Minnesota. Editors include Robert Prouty, Gary Smith, and Charlie Lakin, all three recognized experts in the field of developmental disabilities. This book is a compendium of statistics regarding residential services for people with DD in all 50 states. To quickly summarize, the trend continues to be that of closure of large residential facilities, with Alaska, the District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia having no state operated residential institutions. Many other states (Minnesota, Massachusetts, New York, Pennsylvania, Texas, New Jersey, Wisconsin, and others) have closed most of their state hospitals and/or are significantly downsizing state hospitals. Conversely, the number of community residential settings continues to grow.

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3-8-04  
Attachment 1

President Bush's New Freedom Initiative and the Supreme Court rulings in Olmstead and Fisher v. Oklahoma cases also show increasing preference for people with disabilities to live in their own homes and communities. Clearly the movement of people with developmental disabilities out of large congregate settings and into community residential services is growing. Finally, even in Kansas we see the trend. There are only 277 people with DD living in private intermediate Care Facilities (ICF/MRs) and there is only one large ICF/MR left in Kansas, down from 8 facilities in 1990. The rest closed because the demand for such facilities is not there.

At their August meeting the Council voted unanimously to support closure because it benefits both the people and the system. Desired outcomes of hospital closure include:

- Greater independence for those with developmental disabilities;
- Guaranteed placement in the individual's Least Restrictive Environment;
- Better quality of life for the individual (see report from the closure of Winfield State Hospital and training Center (WSH&TC));
- Savings of \$5,000,000 per year from the closure of one hospital that could be used to reduce current waiting lists; and
- Increased life expectancy, former Winfield staff informed us that at the hospital well over ten people died every year. In the community those same medically fragile people have experience a death rate of under five persons.

Senate Bill 531 includes a Commission of experts whose charge is to study and review the current developmental disabilities systems and provide a report that includes the following (from page 2):

- (1) A recommendation recommending the closure of one developmental disabilities institution no later than January 1, 2006, and recommendations for the closure or the downsizing or other reduction of the other developmental disabilities institution;
- (2) a date of closure for each developmental disabilities institution recommended for closure;
- (3) recommendations of policies and procedures to facilitate any such closure and to assist developmental disabilities institution clients displaced by any such closure or downsizing or other reduction;
- (4) recommendations on service and program changes to ensure that the supports, services and capacity are available to properly serve persons with developmental disabilities at the community level; and
- (5) recommendations on transitional and long-term funding for such services and programs at the community level.

In addition, the Commission must consider the savings and impact of community services, the impact of closure on consumers and their families, the impact on quality of services, a requirement that any savings be put back into the community, and new ways of funding community-based services.

We support this bill because it provides the opportunity of doing planning for both hospital and community services. It also provides several months for this planning. Currently I serve on the committee created by the Special Committee on Appropriations/Ways and Means. We have exactly five weeks in which to study both state hospitals and community intermediate care facilities for developmental disabilities. Five weeks is nowhere near enough time to accomplish our task. However, we have generated information that could be used by this Closure Commission.

Attachment 1 details waiting list numbers and information about the individuals currently residing at KNI and PSH&TC. As of March 2, 2004 there are 1,167 individuals with DD who are waiting for services, who receive nothing. There are 1,506 individuals who are now receiving services but are in need of additional services. The breakdown between adults and families with children are shown on the list. We are extremely grateful that you provided additional funds during the 2003 Legislative Session to serve some of these individuals and we do appreciate all you have done over the years.

Unfortunately, these funds will not serve the number initially projected because community services were underfunded last year, and we had to pend money from 2003 to 2004.

At the same time, we believe a majority of the individuals currently residing at KNI and PSH&TC, would be better served in the community. Therefore, I would like to call your attention to the data attached regarding state hospitals. Of the 364 people who now live in a state hospital, only 123 (33.7%) are at Tier One Level, which is the highest level of severity. These are not medically fragile individuals, and less than 38 of them live in the sexual treatment unit.

In addition, regarding those who have the most severe disabilities, we can match them with individuals who have the same severity level who have never been in the institution or who have been there and moved to the community. Families and guardians are concerned that moving their son or daughter to the community could result in a loss of services. Hospitalization is an entitlement. Once placed in an institution, that individual receives whatever services are needed regardless of the cost. The same cannot be said for the community. To allay the fears of community placement, parents need to be assured that their son or daughter will have access to the same or similar safety net while in the community.



Will there be challenges? Yes. Can Kansas step up to the plate? Yes. Issues which are not on the list, with possible solutions are found in Attachment 2. This list of recommendations for Hospital Closure was developed by Gina McDonald (Kansas Association of Centers on Independent Living), Stephanie Wilson (Alliance), Kathy Lobb (Self Advocate Coalition of Kansas), and others.

I have also provided an Executive Summary of *Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators* by the National Conference of State Legislatures, *Deinstitutionalization of People with Mental Retardation And Developmental Disabilities in the United States: Was This Good Social Policy?* and *Are People Better Off? Outcomes of the Closure of Winfield State Hospital* by James Conroy, and *Lets Face the Real Issues* by Steve Eidelman, Renee Pietroangelo, James Gardner, George Jesien, and Doreen Croser. We endorse SB 531 and urge you to favorably pass it. We do so because we believe it is the right thing to do for people with developmental disabilities.

As always, I greatly appreciate the opportunity to provide you this information and would be happy to answer any questions.

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# State Developmental Disabilities Data State Fiscal Year 2004

## Developmental Disabilities Waiting List Numbers As of March 2, 2004

### Unserved DD Population

Adults	628
Families with DD children	539
Total	1167

### Underserved DD Population

Adults	939
Families with DD children	567
Total	1506

**Grand Total both Lists= 2673**

Attachment 1

## Developmental Disabilities Hospitals Data

Agency	Average Converted Score	Licensed Capacity	% Lic Capacity	Current Population	Openings	More Severe - - - - Less Severe					ICF Rate as of 3/1/03	Projected SFY 04 Costs at Lic capacity	Annualized Total for Day/Res Services	Difference ICF rate vs HCBS rate
						Tier 1	Tier 2	Tier 3	Tier 4	Tier 5				
KNI	161.55	454	38.30%	174	279	89	37	36	20	2	\$369.00	\$23,499,396	\$10,541,997.40	\$12,957,398.60
PSH	119.7	226	56.50%	190	146	34	36	48	56	18	\$309.00	\$21,487,860	\$8,487,057.90	\$13,000,802.10
		680		364	425	123	73	84	76	20		\$44,987,256	\$19,029,055.30	\$25,958,200.70
													<b>Potential Savings</b>	

## State DD Hospital Closure Recommendations

September 22, 2003

General: The following are general recommendations:

- Use the closure of Winfield State Hospital and Training Center (WSH&TC) closure as the model with some modifications.
- Begin closure plans for one hospital immediately. Plan for closure of the second hospital within five years.
- The majority of the persons residing in the facility should move to the community of their choice.
- All money saved from closure if not needed for the institutions' residents in the community, must be used for community services for people with developmental disabilities.
- Stabilize current community services funding in order to allay concerns of parents and service providers regarding future loss of services.

The following Steps are those recommended by the Hospital Closure Work Group:

Step 1: Develop timelines for closure of the facility;

Step 2: Hire a consultant with no ties to the issue to be in charge of closure for oversight and contact purposes;

Step 3: Develop an agreement with the Community Developmental Disabilities Organization in each area to assist the consultant in the movement of the individual to the community;

Step 4: Contact each CDDO of record with list of parents/guardians in their area, the CDDO will be in charge/responsible for Community Integration Planning;

Step 5: Set up contacts for parents/guardians with WSH&TC parents/guardians, SRS staff, community service providers, and others who can be of assistance;

Step 6: Contact parents/guardians regarding the future of institution, include deadlines/timelines/options in the letter;

Step 7: Ensure that Medicaid funds follow the person to the community and, if needed, reasonable start up costs for community integration and special tier rates are provided;

Step 8: Provide a benefits package for those state employees who work at the facility similar to the one provided for WSH&TC employees; and

Step 9: Convene a joint State/County/City entity to make recommendations for use of facility after closure.

# Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators

By DeWayne Davis, Wendy Fox-Grage, and Shelly Gehshan

## Executive Summary

In June 1999, the U.S. Supreme Court addressed the debate about appropriate care options for people with disabilities. In *L.C. & E.W. vs. Olmstead*, the court ruled that states are required to provide community-based services for people with mental disabilities if treatment professionals determine that it is appropriate and the affected individuals do not object to such placement. The Court further concluded that states are responsible for community-based placement if they have the available resources to provide community-based services. States that maintain waiting lists must make a good faith effort to move those on the list to community programs at a reasonable pace.

This report provides profiles of states that have made innovative changes in their service delivery systems to increase the number of community-based placements and reduced institutional placements. Using information from interviews from state disability service agency directors, academics, advocates and state policymakers, this report answers the following questions:

- \* How far along are states in deinstitutionalizing their disabled populations?
- \* What percent of disabled people live in community settings and in state hospitals?
- \* What kinds of medical and social services do these populations need, and what are the service gaps?
- \* Are there any models of care that could be considered "best practices" for states?
- \* What are the costs associated with care for this population, and how are services funded?

The report finds that states have great flexibility through traditional Medicaid and Medicaid Home- and Community-Based Waiver programs to redesign their disability service delivery systems to emphasize community-based placement for persons with mental retardation and other developmental disabilities (MR/DD) who are capable of living in the community. Increased communication and cooperation among those with MR/DD and their families, state agencies, providers, policymakers and advocates have been instrumental in transforming systems that have relied too heavily on institutions to serve disabled populations.

The report also finds great variation in state progress and approaches to deinstitutionalization. Nine states and jurisdictions-Alaska, the District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia-have closed all their public institutions. These states are considered the successful models of deinstitutionalization and the pioneering examples of states that have created community-based delivery systems for their developmentally disabled populations. In addition, states like Michigan, Minnesota, Colorado and West Virginia have taken progressive steps to decrease the number of persons with MR/DD who are housed in public institutions.

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Attachment 2

The report concludes that, although barriers exist in some states that keep them from moving completely to a community-based service delivery system, states can use a number of strategies and proposals to eliminate their reliance on institutional care. These strategies include:

- \* Building community resource networks and community crisis/emergency response systems to address the reason people initially are institutionalized;
- \* Creating systems of long-term care for people with disabilities that are more consumer-driven and include more home-and community-based services;
- \* Developing guidelines that reflect the state's individual MR/DD populations and regional variations;
- \* Emphasizing the search for better ways to treat disabled individuals both medically and socially;
- \* Experimenting with various payment models for personal assistance services, such as direct payment for services and vouchers;
- \* Convening a task force of legislators, state agencies, providers, and people with developmental disabilities and their families to discuss and report on the service needs of people with developmental disabilities;
- \* Establishing a statewide data-collection system that identifies people with developmental disabilities, their demographic and personal characteristics, and their service needs; and
- \* Appropriating money to operate both the institutional and community services until a community-based infrastructure can be developed.

Deinstitutionalization of People with Mental Retardation  
and Developmental Disabilities  
in the United States:  
Was This Good Social Policy?

Revised and Edited in January 2004

Submitted by: The Consortium for Quality Designs  
to the The Arkansas Department of Human Services

**Authored by: James W. Conroy, Ph.D.**

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Senate Ways and Means  
3-8-04  
Attachment 3

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## Purposes of this Paper

The purposes of this paper are to present, explain, and support the following facts and opinions:

**1) Research Shows Multiple Benefits of Community Placement:** Twenty-five years of developmental disabilities research literature on movement from institutional to community settings indicates that, on the average, people experience major enhancements in dozens of quality of life indicators. The literature is remarkably consistent in this area. A handful of recent reports on mathematical models of mortality, led by one researcher in California (Strauss), have been shown by Lakin (1998) to be founded on erroneous data. Claims of higher risk of mortality in community living are scientifically unfounded, and are strongly contradicted by other published studies. No other researchers have replicated the Strauss et al. findings. The sum total of rigorous studies over a 25 year period provide conclusive evidence of the superiority of community living. In 1997 and 1998, my staff individually visited 1,125 people of the more than 2,300 people who moved out of California's Developmental Centers to community homes under the terms of the Coffelt settlement. We will summarize the results of that body of work, which resulted in 17 formal public reports. Their qualities of life are enhanced, they are more independent, they display less challenging behavior, their homes are more pleasant, and their families believe that they are far "better off" than they were in developmental centers.

**2) Deinstitutionalization in Developmental Disabilities Must be Clearly Differentiated from Deinstitutionalization in the Mental Health Field:** The deinstitutionalization of nearly 100,000 American citizens with developmental disabilities has been highly successful. This is a very different experience from the nation's failure to support people with mental illness who have left mental health institutions.

**3) Family Attitudes Change Dramatically:** Families (parents, siblings, other relatives, guardians, next friends) of people living in institutions overwhelmingly support the continued existence of those institutions, and the continued placement of their relatives in them. However, in cases in which people have moved to the community (either over family objections, or after the family's objections have been accorded a formal hearing and they have agreed to trial placements), the families' attitudes change dramatically toward acceptance and support of community living. Even the most vocal opponents of community placement have become ardent supporters of community living once it has been experienced. Recent work in Oklahoma has shown the most dramatic changes in family opinions yet documented (Conroy, 1999). But the same changes have occurred among California's families, as well (Conroy & Seiders, 1998).

**4) The Theory of the "Must Stay" Group is Not Supported:** The classic four reasons given for keeping people in large segregated settings (severe retardation, challenging behavior, medical fragility, and advanced age) have been convincingly discredited by carefully controlled studies of community placement, by the evidence from total closures during the past 25 years, by the fact that 10 states are now entirely free of public institutions as an option, and by the pattern of recent placements out of developmental centers in California.



**5) Community Support Systems are More Cost Effective than Institutional Systems:** All studies published thus far are consistent. Community service models are less costly than institutional models. It must be recognized, however, that this is because staff salaries and benefits are significantly lower in community service systems than in institutional ones. Hence, the most appropriate conclusion is that community services do cost less, but they should not. Moreover, community services are able to obtain Federal reimbursement at the same rate as developmental centers in California.

**6) The Research Findings Are Remarkably Consistent:** The research on this question is very unusual. It is consistent and compelling. The only exception of which I am aware is the mortality studies performed by Strauss, which has been discredited by Lakin, and repudiated by his own colleagues and by his mentor.

**7) Community Living is Not Without Problems, and Requires Protections**

These topics are discussed in greater detail within this paper.

**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**

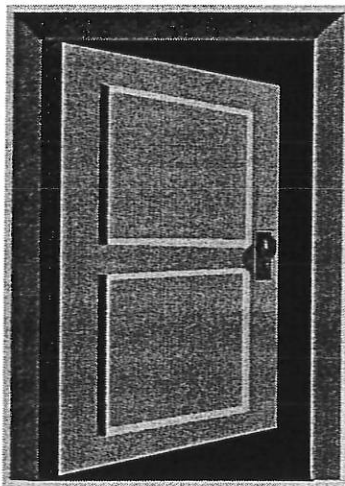
**Submitted to:**  
The Kansas Council on Developmental Disabilities  
And  
The Legislative Coordinating Council

**Submitted by:**  
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**December, 1998**

Senate Ways and Means  
3-8-04  
Attachment 4

“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.

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## 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

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

## Overview

For many years, like the rest of the nation, Kansas has conducted a gradual deinstitutionalization of people with mental retardation. Winfield State Hospital has recently closed. Most of the closure has been accomplished by helping people move into small integrated homes in regular neighborhoods. These people moved during the period between 1996 and 1998.

The present report is the sixth in our series, and it is the first that reports hard scientific data on the well-being of the people who left Winfield. The central question of this Report is “Are they better off?” We can now compare dozens of qualities of life measures for the people when they were at Winfield to the measures now, in their new homes. The specific primary questions for this Quality Tracking Project are:

- **Are the people better off, worse off, or about the same?**
- **In what way(s)?**
- **How much?**
- **At what cost?**

These are the central questions about well-being that any parent, friend, advocate, or caring professional must ask. But our research was also designed to formative (giving insights along the way) as well as summative (evaluating success at the end). Hence we have issued five reports along the way, based on interviews, surveys, focus groups, and knowledge of national models.

When the decision was made to close the institution, it was made for many complex and often political reasons. But at no time did any of the stakeholders plan or hope for harm to these people. To the contrary, most participants believed

(partly on the basis of 20 years of past research) that the peoples' lives would actually be enriched by movement from institution to community.

However, the political reality of the situation in Kansas included skeptics and critics. For all of these caring people on either side of the issue, for the media, for the legislature, for the executive branch, and for public accountability in general, this Report answers the central questions.



## Historical Context

Deinstitutionalization is not a new phenomenon. In the field of developmental disabilities, it has been proceeding since 1969, and has been remarkably well studied, evaluated, and documented. There has, however, been considerable confusion between deinstitutionalization in the mental health field and deinstitutionalization in the mental retardation field.

The misunderstanding is largely due to the historical confusion of mental illness with mental retardation. State institutions for people with mental illness experienced an entirely different, and devastatingly negative, depopulation movement during the 1960s and 1970s (Bassuk & Gerson, 1978).

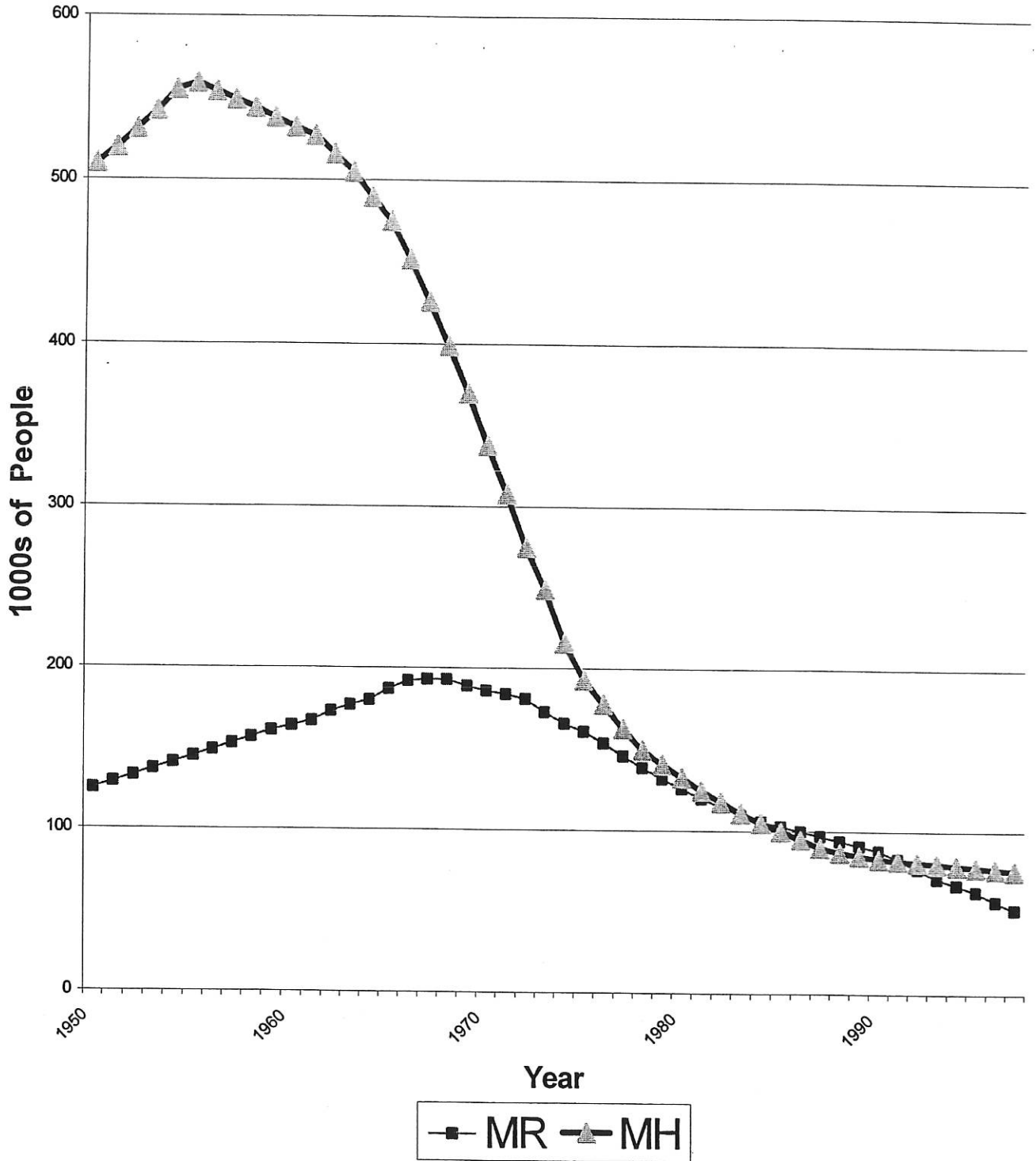
Deinstitutionalization of people with mental illness in the 1960s and 1970s was done hastily, without supports, and largely with reliance on the “new miracle drugs” approved by the FDA in 1955 (the anti-psychotic drugs including Haldol, Mellaril, Thorazine, and so on). The phrase “dumping” came from the fact that tens of thousands of people were simply “discharged” with 30 days of “miracle drug” with no place to live, no job or day activity, and no support to reestablish family relationships. In a summary statement of the nation’s early experience with deinstitutionalization in the mental health field, Alexander (1996) wrote:

Following the deinstitutionalization of persons with serious mental illness from state hospitals, many persons with serious mental illness did not receive the care that they needed and encountered unexpected negative experiences. Among the negative experiences were frequent rehospitalizations, involvement in the criminal justice system, and homelessness.

The result in the mental health field was a national disgrace, according Bassuk & Gerson (1978).

The following figure compares the two trends toward deinstitutionalization. The upper line shows the depopulation of mental health institutions since 1950, which was clearly far more precipitous than the relatively gradual shrinkage of institutions for people with mental retardation in the lower line.

**Figure 1**  
**Deinstitutionalization in the United States:**  
**Mental Retardation vs. Mental Illness, 1950-1997**



The figure shows how different the two trends have been. Most citizens, and many families, who are skeptical of deinstitutionalization, formed their opinions with regard to the mental health debacle. Beginning in 1955, thousands of people with severe mental illness were released from public institutions with little more than 30 days of medications to support them. The term “dumping” was coined to describe this process in the 50s, 60s, and 70s.

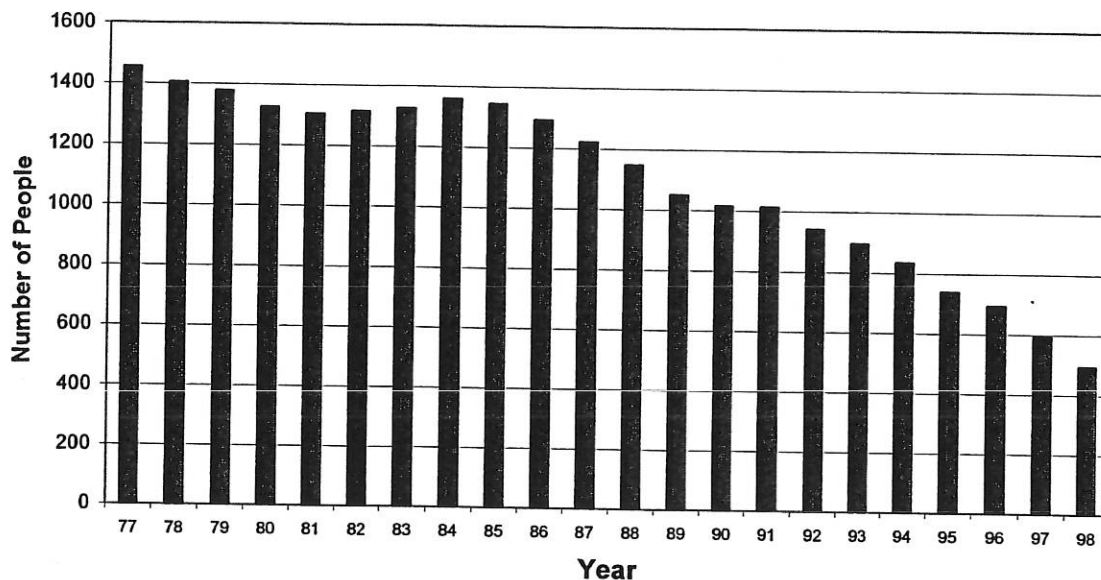
More recent experiences with mental health deinstitutionalizations have been hailed as significant success, such as the closure of Byberry in Philadelphia. Still, it is important to understand the stark difference between the national record in mental illness, versus that for mental retardation and developmental disabilities. In the case of people with developmental disabilities, moving from large institutions to small community homes has been extremely successful. In fact, from the large body of research evidence now available, we are able to make this statement:

*Deinstitutionalization of people with developmental disabilities in America has been one of the most successful and cost-effective social experiments in the past two decades.*

For readers who care to review some of the extensive research literature on this topic, we have available thorough reviews of the largest and longest lasting studies of the impacts of deinstitutionalization in the mental retardation field. One such meta-analysis was performed by Larson & Lakin (1989).

The closure of Winfield is part of a long process of downsizing and privatization in Kansas. The decline of public institutional populations in Kansas is shown in Figure 2.

**Figure 2:  
The Decline of Institutional Populations in Kansas  
1977 to 1998**



The Kansas achievement can now be placed into the context of the national experience of deinstitutionalization. In the case of the Pennhurst Center (a Pennsylvania institution near Valley Forge), more than 1,100 people moved to new community homes between 1978 and 1987. The Pennhurst closure was one of the most hotly contested and extensively studied of its kind. Similarly, other famous community placement processes have been studied and documented, such as:

**Table 1**  
**Prior Studies of Closure and Deinstitutionalization**

<b>State</b>	<b>Time Period</b>	<b>Notes</b>
Arizona	1992-1997	Closed Ft. Stanton 1996, one left
Arkansas	1983-86	Slow depopulation studied by Rosen (1985)
California	1993-1998	Coffelt settlement, 2400 movers, largest and fastest in history
Connecticut	1985-1994	Mansfield closed 1994
Louisiana	1980-1998	Gary W. or "Texas Children" lawsuit brought 600 back to LA, and then into community
Maine	1990	Pineland closed, only one Center left
Michigan	1975-1995	Plymouth Center and others closed during 20 year buildup of community capacity, led by Macomb-Oakland Regional Center; only 250 people with mental retardation still in institutions, largest state to be almost institution-free
Minnesota	1980-1998	Rapid downsizing of all facilities, closure of some
New Hampshire	1992	Became first state to have no citizen in a public institution
New Jersey	1988-1998	Johnstone closed 1991, North Princeton closed 1997
New Mexico	1996	Became institution-free with closure of last public facility
New York	1994	Governor announced goal of no institutions by 2000 (not currently keeping up with goal)
North Carolina	1991-1998	Thomas S. lawsuit results in movement of nearly 1,000 people with dual diagnosis out of Psychiatric Hospitals
Oklahoma	1988-1992	Hissom Memorial Center closed under court order, but ahead of schedule, with the best outcomes yet measured anywhere (Conroy, 1996)
Pennsylvania	1978-1987	Took 9 years to close Pennhurst, most closely studied closure of all time
Rhode Island	1995	Became institution-free after a long policy of community placement
Vermont	1996	Became institution-free
West Virginia	1985-1998	Continual gradual process of placement and closure

The Kansas experience, which was not court-ordered, has been similar in many ways to these prior events, and has also been unique in several ways.

The driving force in the Kansas process appears to have been the Hospital Closure Commission. The Commission worked for many months, heard public testimony, and reviewed hundreds of documents. Following the same process developed by the armed forces for selecting military bases for closure, and after revising its own initial recommendations, the Commission finally recommended two closures, Winfield State Hospital and Topeka State Hospital.

What has resulted from this rapid process of community placement? We at the Center for Outcome Analysis have been studying this issue since the end of 1996. We have measured dozens of qualities of life among the people affected by the community placement process. Our research questions have been intentionally simple: We have pursued our investigations with widely used and recognized measurement instruments and a variety of research designs (face to face key informant interviews and focus groups, telephone and mail surveys, pre and post measurements of qualities of life). We have at all times striven for scientific objectivity to answer the question, "Are people better off?"

Where we have found positive outcomes, we have reported them scientifically. Where we have found problems, we have documented them and suggested actions for improvement.

We cannot fail to note the highly charged political atmosphere surrounding the Kansas closure efforts. We assembled press clippings from the two year period before the Closure Commission announced its decision. The media coverage made it clear that closure issue was a political "hot potato." Suggestions by the Governor were met with negativity in the media, followed by hints from the legislature about the need for closure and consolidation, which also received harsh

coverage. The Closure Commission was created as a fair and impartial way of hearing all sides and coming to a reasonably democratic decision.

In nearly all media coverage, as we read it, the central issue became jobs. In Winfield, the institution employed as many as 1,500 people at times, according to reports. In such a small city, that is significant indeed. The only other large industry in Winfield had shut down not long before the Winfield closure was announced. In all the newspaper clippings, it is difficult to find any mention of what might be best for the people living at Winfield State Hospital.

In selecting the economic focus, the media actually contributed to a process called "commodification" (Felty, 1997). That is, people with developmental disabilities were depicted as commodities rather than as people. The town's economy needed the Winfield residents in order to remain economically solvent.

Thinking of the Winfield residents as commodities also helped promote the notion of keeping them in Winfield, thereby keeping jobs in Winfield. In fact, this is the way the situation was finally resolved. Compromises were made in which nearly 100 of the Winfield people would not return to communities closer to their homes and families (if any) but rather remain in the town of Winfield. In our years of studying institutional changes and deinstitutionalization, this is the first time we have seen such a small town absorb so many people with developmental disabilities into its own housing market. The Winfield closure is therefore unique in this regard.

It was our mandate to determine the human impacts of this unusual form of deinstitutionalization. It is important to point out that our evaluative efforts have been conducted in the midst of serious political and ideological battles. The issue of institutional living versus community living arouses strong passions in the public, the media, and all three branches of government. Within SRS there have been vocal opponents of closure, as well as vocal supporters. This has resulted in



extraordinary confusion, as well as downright difficulty, in obtaining access to the information we needed in order to complete our mission.

Despite the political and emotional context of the Kansas deinstitutionalization, it was essential that we continued to address the ultimate questions in an objective manner: In what kind of service system do people enjoy the highest qualities of life? Where do people experience the most growth, social adaptation, opportunities for choice, and satisfaction? What are the comparative costs of institutional versus community models?

This report is intended to be brief, minimally technical, and graphically oriented, in order to make the findings accessible to the largest possible number of interested parties. Nevertheless, the report is founded on rigorous scientific and statistical analyses.

## Methods

In this Methods section, we provide the information necessary for others to judge the scientific merits of what we measured, how, and why. The general purpose of a Methods section is to allow other scientists to replicate our work, to see whether they obtain similar results. Replication is the heart of the scientific method; any one study can be erroneous, but if other researchers in other places do the same procedures and get the same results, then we gain confidence in the findings. Secondly, a Methods section enables readers to immediately form judgements about whether we measured what is important, or measured those things in the right ways. The Methods section is composed of Instruments (the measurement devices), Procedures (how we collected the data), and Participants (what kinds of people were included).

### **Instruments: The Personal Life Quality Protocol**

Our package of measures of qualities of life is generally called the Personal Life Quality Protocol. Many of the elements of this package evolved from the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Pennhurst Class members have been visited annually since 1978. An extensive battery of quality-related data has been collected on each visit. Over the years, other groups have been added to the data base, such as all people living in Community Living Arrangements in Philadelphia who were not members of the Pennhurst Class.

The battery of instruments was based on the notion that "quality of life" is inherently multidimensional (Conroy, 1986). It is essential to measure many kinds of individual outcomes to gain an understanding of what aspects of quality of life have changed over time (Conroy & Feinstein, 1990a). Modifications made to the battery of instruments over the years have been based on the concept of "valued

outcomes" (Conroy & Feinstein, 1990b; Shea, 1992). Professionals may value some outcomes most highly, such as behavioral development; parents and other relatives may value permanence, safety, and comfort more highly; and people with mental retardation may value having freedom, money, and friends most highly. The goal in our research on deinstitutionalization, and later in self-determination, has been to learn how to measure aspects of all of these "valued outcomes" reliably.

The measures used in 1998 included behavioral progress, integration, productivity, earnings, opportunities for choicemaking, Individual Habilitation Plan status, health, health care, medications, amount and type of developmentally oriented services, satisfaction of the people receiving services, satisfaction of next of kin, physical quality, individualized practices, staff longevity, and program cost. Some of the data collection instruments, and their reliability, have been described in the Pennhurst reports and subsequent documents (Conroy & Bradley, 1985; Devlin, 1989; Lemanowicz, Levine, Feinstein, & Conroy, 1990).

### **Behavior**

The behavioral measures were usually shortened forms of the original AAMR Adaptive Behavior Scale (Nihira, Foster, Shellhaas, & Leland, 1974). The first part contained 32 items on adaptive behavior, and the second, 15 items on the frequency of challenging behaviors. The measures were shortened on the basis of the mathematical criteria of factor structure and reliability. According to Arndt (1981), the best way to treat these type of data is as two simple additive scales, one reflecting adaptive behavior and the other challenging behavior. The adaptive behavior sum score has been found to be highly reliable (Devlin, 1989), with an interrater reliability of .95 and test-retest reliability of .96. For the maladaptive behavior section, interrater reliability was .96 and test-retest was .78.

In some of our data sets (New Hampshire and California), the California behavior scales called the Client Development Evaluation Report were used. This behavior measure is composed of 52. The CDER adaptive behavior measure has been reported to have good reliability under certain circumstances (Harris, 1982). It should be noted that this is not a direct test of adaptive behavior, but rather a rating scale in which the opinions of knowledgeable third party informants are taken as descriptions of adaptive behavior.

### **Choice Making**

The scale of choice making is called the Decision Control Inventory. It is composed of 35 ratings of the extent to which minor and major life decisions are made by paid staff versus the focus person and/or unpaid friends and relatives. Each rating is given on a 10 point scale, where 0 means the choice is made entirely by paid staff/professionals, 10 means the choice is made entirely by the focus person (and/or unpaid trusted others), and 5 means the choice is shared equally. This is the same scale being used by the Robert Wood Johnson Foundation in its National Evaluation of Self-Determination in 29 states. The interrater reliability of the Inventory was reported as .86 (Conroy, 1995). (A separate form was recently developed for people living with their families rather than being supported by paid staff. In that form, the power balance is measured between the person and the relatives.)

### **Integration**

The scale used to assess integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986). It measured how often people visit with friends, go shopping, go to a place of worship, engage in recreation, and so on, in the presence of non-disabled citizens.

The scale tapped only half of the true meaning of integration; if integration is composed of both presence and participation, then the Harris scale reflects only the first part. Presence in the community is a necessary but not sufficient condition for participation in the community. The scale simply counts the number of “outings” to places where non-disabled citizens might be present. The scale is restricted to the preceding month. The interrater reliability of this scale was reported to be very low when the two interviews were separated by 8 weeks, but very high when the time interval was corrected for (.97).

### **Perceived Quality of Life Changes**

The “Quality of Life Changes” Scale asks each person to rate his/her quality of life “A Year Ago” and “Now.” Ratings are given on 5 point Likert scales, and cover 13 dimensions of quality. On this scale, we permit surrogates to respond. Surrogates (usually staff persons) were “whoever knew the class member best on a day to day basis.” On this scale, approximately 85% of the responses are provided by surrogates. The interrater reliability of the Quality of Life Changes Scale was found to be .76.

### **Health and Health Care**

The indicators of health and health care were simple and straightforward. Intensity of medical needs was rated by staff informants on a four point scale. Problems involved with getting health care for the person were rated on a three point scale (No Problems, Minor Problems, Major Problems). Number of days of restricted activity because of health problems, number of medications received daily, and percent receiving psychotropic medications, were scored as raw frequencies. Frequency of seeing physicians, of seeing specialists, of seeing

dentists, of going to emergency rooms, and so forth were also included. The name and type of every medication was also collected.

### **Productivity**

Productivity was reflected by earnings, by the amount of time engaged in daytime activities that were designed to be productive (adult day activities, vocational training, workshops, supported and competitive employment), and by the amount of time reported to be engaged in developmentally oriented activities in the home. Through the instrument package estimates were made of the amount of each of 17 services delivered in the preceding 4 weeks, such as dressing skills training, occupational therapy, and behavioral interventions.

Many versions of the PLQ also contain the "Orientation Toward Productive Activities" scale, composed of 14 simple items concerning being on time, showing enthusiasm about work, keeping a job, and getting promotions. This scale has not yet been subjected to reliability testing. It did, however, show significant increases during the first New Hampshire implementation of self-determination, so there is some reason to believe that it is sensitive to meaningful changes.

### **Size of Home**

The size of the home was measured by the response to the question "How many people who have developmental disabilities live in this immediate setting?" This was not necessarily a direct measure of quality or outcome, but the size of the setting has been investigated extensively as an important contributor to quality of life (Balla, 1976; Baroff, 1980; Conroy, 1992; Lakin, White, Hill, Bruininks, & Wright, 1990).

### **Physical Quality of the Home**

The Physical Quality Index was modified from Seltzer's (1980) instrument, which was in turn derived from portions of the Multiphasic Environmental Rating Procedure (Moos, Lemke, & Mehren, 1979). It was a measure of how home-like and pleasant the setting was. It was completed after the visiting data collector had walked through the residence, rating each room on dimensions such as cleanliness, odors, condition of the furniture, individualized decorations, and overall pleasantness. Interrater reliability of the PQI was reported as .81, with test-retest at .70 (Devlin, 1989).

### **Individualized Treatment**

The Individualized Practices Scale was used as an indicator of individualized versus group-oriented practices in the home. This instrument was derived from the work of Pratt, Luszcz, and Brown (1981), which was based on the Resident Management Practices Inventory developed by McLain, Silverstein, Hubbel, and Brownlee (1975). The Inventory was an adaptation of the Child Management Scale from the pioneering work of King, Raynes, and Tizard (1971) on measurement of resident-oriented versus staff-oriented practices. The Individualized Practices Scale was administered during interviews with individuals familiar with the residential practices in the home, and took about 5 minutes to complete. Devlin (1989) reported interrater reliability of .78 and test-retest of .86.

### **Subjective Impressions**

The Visitor Subjective Impressions were subjective ratings on a scale of 1 to 10 about overall perceptions of the quality of the residential site, quality of food found in the refrigerator and cupboards, quality of staff-consumer interactions,

quality of consumer-consumer interactions, expectations of staff regarding consumers' potential for growth and development, and the degree to which the setting was oriented toward research and measurement. The visitors made these ratings after being in each home for an average of 3 hours. Reliability of these essentially subjective ratings has not been adequately tested. They remain as subjective impressions, and should be interpreted with caution.

### **Service Delivery Process**

A few simple items were collected to reflect the involvement of the case manager according to records. Examples were a recording from the log book of when the case manager last visited, the presence of an up-to-date IHP at the time of the visit, and the presence of the Day Program Plan at the home.

The PLQ also contained an instrument to capture the type and amount of formal services rendered to the person. Estimates were made of the amount of each of 17 services delivered in the preceding 4 weeks, such as dressing skills training, occupational therapy, and behavioral interventions.

The most recent PLQ package developed for the self-determination evaluation contains a new section on the Person-Centered Planning Process. One scale is designed to measure the degree to which the planning process had the characteristics of "person-centeredness." Another captures the membership of the planning team, according to paid or unpaid, invited or not invited by the focus person, and family member or not. Another page captures each goal, desire, or preference in the Plan, plus the degree to which each goal is being addressed by formal or informal supports, and the extent of progress seen thus far toward the goal. These new elements have not been subjected to reliability testing yet.



## Family Survey

A survey was mailed to the closest known relative or friend of every person visited. This "Family Survey" was designed to find out about the families' perceptions of the quality of the person's living and working situation. It also explored families' attitudes and concerns. A Family Survey has been an essential part of the monitoring activities in the Temple research group since the beginning of the Pennhurst Longitudinal Study in 1979. We have examined reliability for a convenient but small sample of families who filled out two survey forms, and found reliability to be very high, but we have not yet published these findings.

## Procedures for Data Collection

The project recruited and trained local professionals, paraprofessionals, and graduate students to perform a data collection visit with each person. These data collectors, called "visitors," functioned as Independent Contractors. They were paid a fixed rate for each completed interview. Here are the written instructions from our Personal Life Quality Protocol that we provide to the visitors:

*This package is composed of many measures, scales, instruments, and interview items. Practically all of the information collected in this package is related to quality of life. In order to complete the package, you must have access to:*

- 1. The person (to attempt a 5 to 15 minute direct interview)*
  - 2. The person's home (for a 5 to 10 minute tour and observation)*
  - 3. Whoever knows the individual best on a day to day basis (average 45 minutes)*
  - 4. The person's records, including medical records*
  - 5. In some cases, a health care professional (about 5-10 minutes)*
- With access to these five sources of information, you should in most cases be able to complete this package within the range of 60 to 90 minutes.*

Initial training for the Visitors was conducted by the Principal Investigator, and later training by the Project Coordinator and the Principal Consultant. The training consisted of an introduction to the project, a role-playing exercise, and a review of the instrument sections and purposes. Field supervision was provided on site during the first few days of visits.

Each visitor was responsible for scheduling appointments and completing an assignment of visits. Visitors were instructed emphatically to respect programmatic needs, and work around them. No person's daily schedule was to be disrupted by these visits. In our community work this year, the average visit took 89 minutes. The amount of information collected, in relation to the relatively short duration of the visits, is worthy of comment. We are able to collect reliable quantitative data on dozens of qualities of life in a very short time, with very little intrusion into peoples' lives.

Collection of such solid information about peoples' qualities of life and outcomes is amply justifiable on an annual basis. There is absolutely no substitute for individual data on quality. No amount of licensing, performance indicators, or accreditation can compare to the utility and precision of individual outcome measurement. As systems move toward person centered planning, they must also move toward person centered evaluation and quality assurance systems.

### **Participants**

The 88 people who are the primary subject of this Report ranged in age from 8 to 79, with an average of 43 years. They were 60% male, and 5% minorities. All 88 were labeled with "profound mental retardation." Of the 88 people, 51 were unable to walk, 17 were reported to have serious aggression problems, there were 23 with severe self-abusive behaviors, 43 with major seizure disorders, 34 with no

vision, and 33 with severe health problems. Obviously, these 88 people experienced a wide variety of severe disabilities. One might infer that, if these people benefited from moving to community homes, then anyone could.

## Results

The ultimate quantitative questions posed by this project were, “Are these people better off, worse off, or about the same, and in what ways, and how much?” For the quantitative part of our work, we visited hundreds of people during this work, interviewed hundreds of staff members, reviewed records, and toured homes and day programs.

The data permitted us to analyze more than 700 items of information. Most of these items were combined into scales for ease of interpretation. For example, there were 16 items on “getting out” and going on outings. The 16 were combined into a single scale of how many times each person went out into integrated settings each month. This produced a simple measure of “how often people got out each month.” If this measure went up, then we would conclude that the level of “integrative activities” increased. That would be a positive outcome, insofar as reduced segregation is viewed as a good thing. There were many similar scales of outcomes.

The following Table 2 shows the outcome variables and the results in statistical terms. The next table, Table 3, translates these scientific findings into verbal form. Each outcome will then be discussed briefly in sequence.

**Table 2**  
**Statistical Summary of Outcomes at Year One**

<b>Quality Dimension</b>	<b>Pre</b>	<b>Post</b>	<b>t</b>	<b>df</b>	<b>P</b>
Adaptive Behavior Scale	33.1	34.8	t=2.19,	87 df,	p=.015
Orientation Toward Productive Activities Scale	1.7	11.5	t=9.79,	86 df,	p=.000
Challenging Behavior	78.6	81.3	t=1.60,	86 df,	p=.056
# of Services in Individual Plan	5.2	8.2	t=6.34,	88 df,	p=.000
Hours of Day Program Services	4.0	18.1	t=6.71,	87 df,	p=.000
Hours of Developmental "Programming" in the Home	577.6	281.1	t=4.64,	86 df,	p=.000
Integration	3.0	30.9	t=10.38,	84 df,	p=.000
Choicemaking	26.6	39.6	t=4.65,	88 df,	p=.000
Qualities of Life Ratings	68.0	78.2	t=6.68,	88 df,	p=.000
Qualities of Life Perceptions of Changes	53.5	78.1	t=12.33,	82 df,	p=.000
Staff Job Satisfaction	7.7	8.9	t=3.87,	87 df,	p=.000
Staff Like Working With This Person	7.8	9.2	t=5.42,	87 df,	p=.000
Staff Get Sufficient Support	3.8	4.7	t=6.78,	87 df,	p=.000
Staff Pay Rate	22K	18K	t=5.24,	61 df,	p=.000
Health Rating	3.5	3.8	t=3.09,	87 df,	p=.003
Health by Days Ill Past 28	3.2	0.8	t=2.93,	87 df,	p=.004
Medications, General	5.7	4.9	t=2.62,	87 df,	p=.010
Medications, Psychotropic	0.4	0.1	t=3.56,	88 df,	p=.001
Doctor Visits Per Year	22.2	5.6	t=7.21,	85 df,	p=.000
Dental Visits Per Year	2.3	0.5	t=12.98,	80 df,	p=.000
Family Contacts	6.6	18.1	t=2.55,	73 df,	p=.000
Individualized Practices Scale	47.3	72.0	t=12.60,	88 df,	p=.000
Physical Quality Scale	76.0	85.9	t=7.15,	86 df,	p=.000
Normalization	47.4	82.4	t=13.29,	87 df,	p=.000
Subjective Impressions of Visitors re: Overall Quality	6.4	7.0	t=2.29,	88 df,	p=.013

**Table 3**  
**Verbal Summary of Outcomes at Year One**

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

Clearly, the overwhelming pattern of these quality of life outcomes is positive. There can be little doubt that, on the average, the Winfield Movers are considerably “better off” in their new community homes. They are better off in most dimensions, but not all.

For adaptive behavior, which is a measure of independent functioning at the level of self-care skills, the three point gain on a scale of 100 points is statistically significant and meaningful. Because it happened in a short time, there is reason to hope that there is still more learning potential to be tapped among these people.

It may be of interest to compare these adaptive behavior outcomes in Kansas to those we have obtained in other states. Table 4 shows these comparisons.

**Table 4**  
**Adaptive Behavior Development**  
**In Several Deinstitutionalization Studies**

<b>State</b>	<b>Number of Years</b>	<b>Time-1 Average Adaptive Behavior Score</b>	<b>Time-2 Average Adaptive Behavior Score</b>	<b>Gain on 100 Point Scales</b>
Pennsylvania	14 years	39.8	50.2	10.4
New Hampshire	8 years	53.0	62.3	9.3
Louisiana	7 years	56.2	64.2	8.0
Oklahoma	6 years	41.3	47.4	6.2
Connecticut	5 years	49.5	54.0	4.5
California	3 years	44.7	46.7	2.0
North Carolina	2 years	52.7	54.8	2.2
<b>Kansas</b>	<b>1 year</b>	<b>33.1</b>	<b>34.8</b>	<b>1.7</b>

Sources: Conroy, 1996b, Conroy & Bradley, 1985; Bradley, Conroy, & Covert, 1986; Lemanowicz, Conroy, & Gant, 1985; Conroy, 1986b; Conroy, Lemanowicz, & Bernotsky, 1991; Present Report; Dudley, Ahlgrim-Delzell, & Conroy, 1995.

As would be expected, the results in Table 4 vary according to how long the people have been out of the institution. The Kansas group has been out the shortest time (many of them were visited at 6 months post-placement), and therefore it is reasonable that these gains are the smallest. However, they also started out with considerably less independence skills than any of the groups in other states. This should be taken into consideration in interpreting the data. In percentage terms, the Kansas group has done very well.

The Orientation Toward Productive Activities Scale measures attitudes and behaviors related to productivity, including work, education, hobbies, volunteer work, self-improvement, etc. This scale's sharp increase from 1.7 to 11.5 points shows major progress toward productive engagement, but with a lot of room to grow on this 100 point scale. The large increase is probably linked to the large shift in formal day activity programs from an average of 4 hours to 18 hours per week.

For challenging behavior, the improvement of 2.7 points out of 100 is borderline statistically significant ( $p=.056$ , not quite reaching the usual criterion of  $.050$ ). The result still seems worth noting, especially when cast into the context of comparison with other states shown in Table 5.



**Table 5**  
**Challenging Behavior Improvements**  
**In Several Deinstitutionalization Studies**

State	Number of Years	Time-1 Average Challenging Behavior Score	Time-2 Average Challenging Behavior Score	Gain on 100 Point Scales
Pennsylvania	14 years	77.7	87.3	9.6
New Hampshire	8 years	79.6	78.6	-1.0
Louisiana	7 years	80.9	84.1	3.2
Oklahoma	6 years	89.7	93.5	3.8
Connecticut	5 years	79.0	80.2	1.2
California	3 years	68.1	76.4	8.3
North Carolina	2 years	87.7	89.4	1.7
<b>Kansas</b>	<b>1 year</b>	<b>78.6</b>	<b>81.3</b>	<b>2.7</b>

In this light, the Kansas Movers have done very well, better than people in some states who have been in the community for several years. We would interpret this as a positive outcome, despite the borderline statistical significance, because this Kansas group is small relative to the studies in other states, and statistical significance is more difficult to achieve with small samples.

Each person has an individual written plan of some kind (support plan, individual program plan, individual habilitation plan, essential lifestyle plan, etc.). The number of goals in the plan has increased from an average of 5.2 to 8.2 since moving to community homes. This can be interpreted in several ways, such as an intense effort among new service providers to get to know the person's capabilities, and greater demands being placed on the person simply by living in a non-segregated setting. More goals in the individual plan is not necessarily a good

thing in itself, but it does suggest that heightened attention is being given to the person's development.

The results for day program services are impressive, going up from 4 hours per week to 18, as noted above. Coupled with the next outcome, which is a decrease in the total hours of developmentally oriented "programming" in the home, a pattern emerges. The community providers have emphasized day activities which take the person out of the home, into a rhythm and pattern of weekly life that includes movement, engagement, and activity. This more closely approximates the routine of life for our culture than did the institutional pattern of having almost all services and activities provided in or around the place where the person sleeps.

The Integrative Activities Scale captures how often the person "gets out" into settings and situations where any member of the general public might go, such as movies, restaurants, shopping centers, and sports events. The large increase from 3 events per month to 31 shows the dramatic change in the Movers' exposure to the mainstream of the culture, and to its people. For context, Figure 3 shows data from the same scale from other states and service types.

**Figure 3**  
**Integration Comparisons Across States and Service Types**

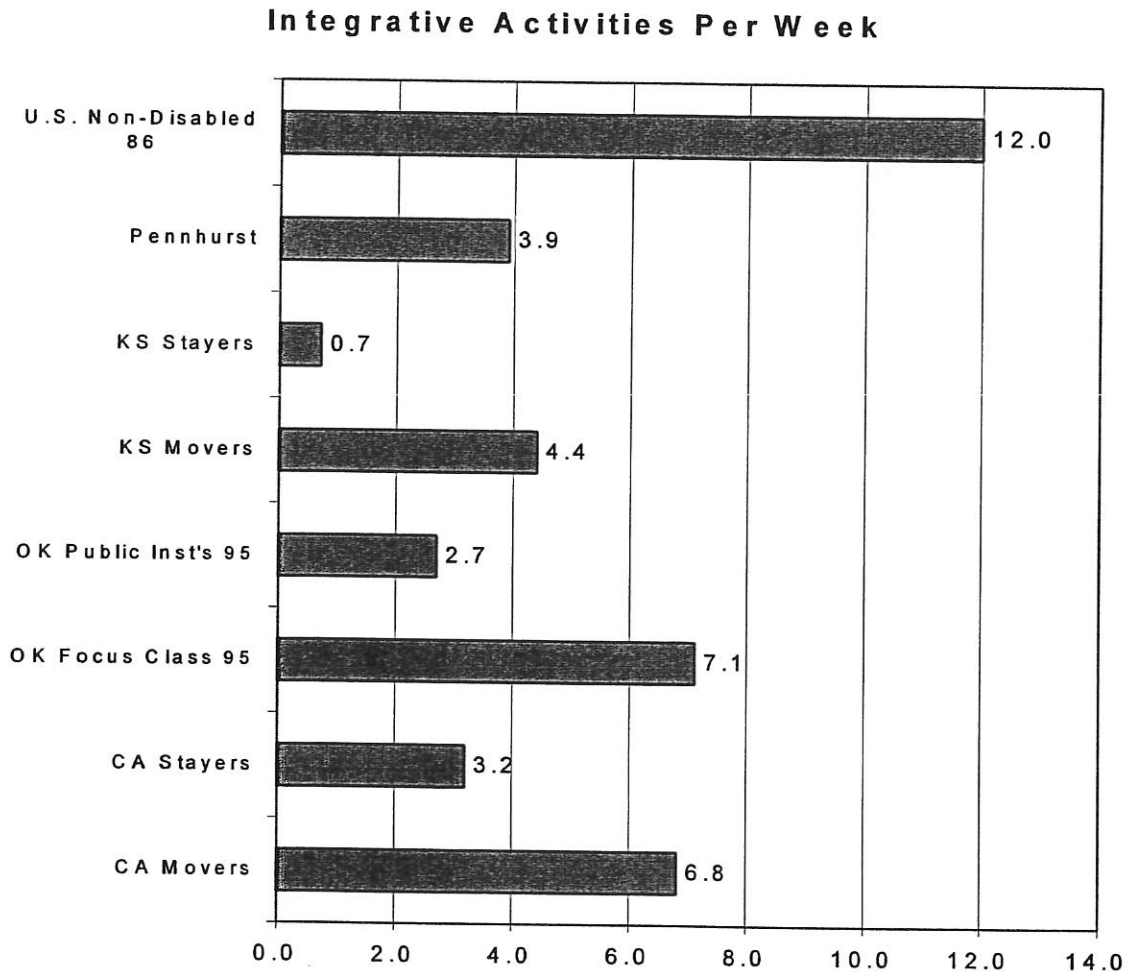


Figure 3 shows that the experiences of the Winfield Movers are not dissimilar to those of Movers in other states. The difference is that the Movers in California and Oklahoma have been out of their institutions longer, and hence have had more time to get into a rhythm of frequent outings.

Our scale of choicemaking, the Decision Control Inventory, has gone up almost 50%, from 27 to 40 points out of 100. Table 6 provides detail about which areas of choicemaking have increased the most and the least. This can provide guidance for providers wishing to strengthen efforts in this area.

**Table 6**  
**Details of Changes in Opportunities for Choice Making**

<b>Dimension</b>	<b>Change</b>
Whether to have pet(s) in the home	4.8
Choice of furnishings and decorations in the home	3.5
What clothes to buy in store	2.6
When to go to bed on weekdays	2.5
When to go to bed on weekends	2.5
Minor vices - use of tobacco, alcohol, caffeine, explicit magazines, etc.	2.5
Choice of places to go	2.2
Choice of which service agency works with person	2.2
What to do with personal money	2.1
Taking naps in evenings and on weekends	2.0
Choosing to decline to take part in group activities	1.7
Choosing restaurants when eating out	1.7
What clothes to wear on weekdays	1.6
When to get up on weekends	1.6
What clothes to wear on weekends	1.4
What to have for dinner	1.3
What to have for breakfast	1.2
Type of work or day program	1.2
What foods to buy for the home when shopping	1.0
Visiting with friends outside the person's residence	0.5
What to do with relaxation time, such as what to watch on TV, what music to listen to, books to read	0.4
Amount of time spent working or at day program	0.2
Time and frequency of bathing or showering	-0.1
Choice of house or apartment	-0.3
Type of transportation to and from day program or job	-0.4
Choice of Case Manager	-0.8
Choice of people to live with	-0.9
Express affection, including sexual	-1.0
Choice of agency's support persons/staff (N/A if family)	-1.1

These data show that the largest change was in the opportunity for people to have pets. Because of the considerable literature on the potentially therapeutic value of pets, this may turn out to be an important change in the long run.

Following that are changes in control over furnishings in the home, clothes to buy,

and bedtimes. These changes should not be surprising, since they have arisen from moving from a hospital-like environment with very strict medically oriented rules and regulations, into more flexible and individually tailored community homes.

Comparisons are particularly interesting in this outcome dimension. For Movers in California over the past 4 years, the Decision Control Scores increased from 31 to 36 points. The Kansas Movers started lower, and wound up higher, going from 27 to 40 points. Both of these groups are quite distinguishable from the people who participated in the original Self-Determination initiative in Keene New Hampshire, who went from an already high starting score of 67 to a score of 72 in 18 months. The Keene system in 1994 had already eliminated nearly all congregate care and work models, and hence the people receiving supports there were already exercising extraordinary levels of choice and participation. The positive side of this comparison is that the Kansas Movers are likely to continue to show improvements year after year as the support system shifts more and more toward self-determination, supported living, and supported employment. We hope these future gains will be measured and documented by the state funding agency.

The measures in this study include a scale of perceived qualities of life. There are 14 dimensions of quality of life in this scale, including health, friendships, safety, comfort, and so forth. The person, or whoever knows the person best at Winfield, gave numeric ratings of the person's qualities of life at that time. A year later, staff in the new community homes give ratings of the same qualities of life. We compare these ratings. For the overall scale composed of the 14 dimensions (which is a 100 point scale), the average score went up from 68 to 78, indicating that the people closest to the Movers at Winfield and then in the community report considerably higher perceived qualities of life in the community.

We also ask the community staff for their perception of these 14 qualities of life THEN (when the person lived at Winfield). By this method, the perceived

improvements are even larger, going from an average of 54 at Winfield to 78 in the community. Taking this “THEN and NOW” method a little further, we can see which of the 14 areas are believed to have changed the most. Table 7 shows these results, sorted by the magnitude of change.

**Table 7**  
**Perceived Quality of Life Changes Among the Movers**  
**As Reported by Staff Who Knew Them Best**

<b>Dimension</b>	<b>Now</b>	<b>Then</b>	<b>P</b>	<b>Change</b>
Food	3.5	2.6	0.000	0.9
Getting out/getting around	3.1	2.3	0.000	0.8
Running own life, making choices	3.0	2.2	0.000	0.8
What he/she does all day	3.1	2.5	0.000	0.6
Relationship with friends	2.8	2.3	0.001	0.5
Happiness	3.3	2.8	0.000	0.5
Comfort	3.4	2.9	0.000	0.5
Privacy	3.7	3.2	0.000	0.5
Overall quality of life	3.5	3.0	0.000	0.5
Safety	3.5	3.1	0.000	0.4
Treatment by staff	3.8	3.4	0.000	0.4
Relationship with family	2.3	2.1	0.318	0.2
Health	2.7	2.6	0.288	0.1
Dental	2.4	2.9	0.000	-0.5

By either method of analysis, the clear conclusion is that the Movers are believed to be “better off” in nearly all of the 14 dimensions. Table 7 presents the details, so that policy makers can see clearly what they already know: there is a problem with acquiring good dental care for these people in the community.

Another dimension of quality in any residential program is related to the staff. Do they like their jobs? Do they like working with this person specifically? Do they feel they receive sufficient support from administration to do their jobs

effectively? If any of us were living in a supported setting, we would certainly want these questions to be answerable with a strong “Yes.”

For “How much do you like your job?” on a scale of 1 to 10, the average response from Winfield staff was 7.7 and in the community it was 8.9, and this difference was significant ( $t=3.87$ , 87 df,  $p=.000$ ). Community staff like their jobs better than Winfield staff did. For “How do you feel about working with this person?” on a scale of 1 to 10, the Winfield average was 7.8, and the community 9.2, again significant ( $t=5.42$ , 87 df,  $p=.000$ ). Community staff report enjoying working with each specific person significantly more than did the Winfield staff.

On “Do you feel you receive sufficient support from administration to do your job?” the figures are 3.7 Winfield and 4.7 community (6.78, 87 df,  $p=.000$ ). Both figures are low, indicating need for management action, but the ratings are still higher in the community than back at Winfield.

It is intriguing in this light to note the disparity in salaries. With every staff respondent who sat down with our visitors to describe the people they worked with, we asked their salaries, although this was optional for them to answer. Sixty-one staff elected to respond. The average annual salary reported to us by Winfield staff was \$22,152, while in the community it is \$18,373 ( $t=5.45$ , 60 df,  $p=.000$ ).

Thus the average community salary was only about 83% of the average Winfield salary. Yet the community staff like their jobs more, like working with the individual Movers more, and report better management conditions. This apparently paradoxical finding mirrors what this research group has found in many other studies, most recently California (Conroy & Seiders, 1998).

In the domain of health and health care, the data show that close associates at Winfield rated the Movers’ general health status lower than did the close associates in the community homes (3.5 versus 3.8 on a 4 point scale), and this was significant ( $t=3.09$ , 87 df,  $p=.003$ ). Another commonly used index of general



health is “days of restricted activity due to illness in the past 28 days,” and this indicator showed 3.2 days at Winfield and now shows 0.8 days in the community. The average number of medications administered daily have decreased from 5.7 to 4.9. In addition the number of psychotropic medications has decreased from 0.4 to 0.1. All of these changes suggest improved health and/or less need for medications, and should be interpreted as positive outcomes.

Indicators of health care utilization, on the other hand, are down. The number of times each person was seen by a doctor averaged 22.3 at Winfield, and is 5.6 in the community. This indicator was an annual figure, and is probably skewed by the fact that we visited many of the Movers before they had been out for a full year. However, this could not explain such a large difference. We must conclude that doctor visits have decreased. This is not necessarily a bad thing. It is possible that 22 visits per year was more than necessary at Winfield, but these speculations demand more detailed research. Comparative data may be helpful. In community programs in Pennsylvania, Nowell, Baker, & Conroy (1989) found that the average person saw a doctor 17 times per year. We therefore urge attention to the Movers’ access to and need for doctors.

Similarly, access to dentists seems to have decreased, from 2.3 visits per year to 0.5. The same cautionary comments apply here, but combining this finding with the Quality of Life Scale finding, it seems clear that dental care is indeed a problem.

We find these health care data to be paradoxical. The closest staff respondents tell us that the Movers are healthier, and that they are receiving fewer medications. At the same time, they are seeing doctors less often. Further investigation with qualitative methods such as case studies could be enlightening.

The frequency of family contacts increased from 6.6 per year to 18.1 per year. Obviously, this could be due to the fact of the closure, and intensely

heightened interest by relatives. This could therefore be a temporary phenomenon. Once the Movers are settled in their new homes, family involvement might drop back to baseline levels. Nevertheless, the increased contact with families must be regarded as a very positive outcome.

There are four general measures of environmental quality in this study: the Individualized Practices Scale, the Physical Quality Scale, the Elements of Normalization Scale, and the Subjective Impressions ratings. These scales are generally completed after the visit, based on the interviews, observation, and a tour of the home.

The Individualized Practices Scale is a very simple 10 item device that taps the degree to which the home is oriented toward flexibility and individual differences versus rules that apply to all. The scale ranges from 0 to 100. This scale shows an increase from 47 to 72 points after moving to community homes.

The Physical Quality Scale examines aspects of the home such as attractiveness, comfort, decorative diversity, cleanliness, and so forth. It is collected room by room, each room is rated separately, and all the scores are combined into a 100 point scale. The average scores have increased from 76 to 86 points.

The Elements of Normalization Scale taps the degree to which the person's situation reflects patterns and rhythms of mainstream society. It has increased from 47 to 82 points out of 100.

The Subjective Impressions items ask our visitors, who have been with or near each Mover for about 90 minutes, to rate how they feel about the home. On the overall quality scale, the average score has increased from 6.4 to 7.0 out of 10.

All of the health and environmental scale changes are statistically significant, as was shown in Table 2.

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## **Appendix A**

### **The Personal Life Quality Protocol**

#### **Kansas Version 1.5**

# Personal Life Quality Protocol

## Kansas Version 1.5

Developed by James W. Conroy, Ph.D.  
The Center for Outcome Analysis  
1062 Lancaster Avenue  
Suite 18C  
Rosemont, PA 19010  
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### General Instructions

This package is composed of many measures, scales, instruments, and interview items. Practically all of the information collected in this package is related to quality of life. In order to complete the package, you must have access to:

1. The person (to attempt a 5 to 15 minute direct interview)
2. The person's home (for a 5 to 10 minute tour and observation)
3. Whoever knows the individual best on a day to day basis (average 60 minutes)
4. The person's records, including medical records
5. A health care professional familiar with the person (about 5-10 minutes)

With access to these five sources of information, you should be able to complete this package within the range of 45 to 95 minutes.

### Introductory Statement (May be paraphrased as needed)

I am \_\_\_\_\_, and I am working on a project for the Legislature and the Kansas Council on Developmental Disabilities. Today, I am visiting \_\_\_\_\_ and collecting information about his/her situation and quality of life. I have the permission of the Department of Social and Rehabilitative Services and the State Hospital Superintendent to do this. I will need about 5 minutes with the person, about an hour to an hour and a half with whoever knows the person best on a day to day basis, plus access to records, a knowledgeable health care professional, and the person's home.

By conducting these visits and collecting information about the person's quality of life, we will be able to scientifically document changes in the person's quality of life during the years to come. Areas of quality include many factors, including the person's satisfaction, family satisfaction, types and amounts of services and supports, health, health care, progress toward increased independence, self-determination, productivity, integration, and quality of home and work settings.

Any questions about this project can be directed to Dr. James Conroy at 610-520-2007. However, we are not permitted to delay the visit for such questions. Our responsibility is to visit each person as soon as possible, so that there will be no delays in this important fact-finding mission.



General Information

1. \_\_\_\_\_ 2. \_\_\_\_\_ 3. \_\_\_\_\_  
First Name M.I. Last Name
4. \_\_\_\_\_ 5. \_\_\_\_\_  
Social Security Number SRS Client ID Number
6. \_\_\_\_\_  
General Name of Residential Service/Support Provider Agency
7. \_\_\_\_\_  
Specific Subagency Name or Division
8. \_\_\_\_\_  
Complete Mailing Address, Including Apartment #, Line 1
9. \_\_\_\_\_  
Complete Mailing Address, Including Apartment #, Line 2
10. \_\_\_\_\_ 11. \_\_\_\_\_ 12. \_\_\_\_\_  
City or Town State Zip Code
13. \_\_\_\_\_ 14. \_\_\_\_\_  
Home Telephone Number Provider Number or Site Code
15. \_\_\_\_\_  
District With Which This Person Is Affiliated
16. \_\_\_\_\_ 17. \_\_\_\_\_  
Primary Respondent's Name Title or Relationship
18. \_\_\_\_\_ 19. \_\_\_\_\_  
Visitor's Name Today's Date

Individual Descriptive Information

1. DATE OF BIRTH  
\_\_\_\_\_
2. AGE  
\_\_\_\_\_
3. GENDER  
1 Male  
2 Female  
\_\_\_\_\_
4. PRIMARY ETHNICITY  
1 Caucasian or White  
2 African-American or Afro-American or Black  
3 Latino or Hispanic  
4 Native American or American Indian  
5 Asian  
6 Other  
\_\_\_\_\_

5. PRIMARY LANGUAGE SPOKEN BY THIS PERSON

6. MARITAL STATUS

- 1 Never married  
2 Married now  
3 Married in past, single now

7. IS THIS PERSON A PARENT?

- 1 No children  
2 Parent with one or more dependent children  
3 Parent, no children dependent at this time

8. LEVEL OF MENTAL RETARDATION LABEL (IF ANY)

- 0 Profound  
1 Severe  
2 Moderate  
3 Mild  
4 Mental retardation present, but no level labeled  
9 Not labeled with mental retardation

9. MENTAL ILLNESS - DSM-IV Diagnoses:

Axis I: \_\_\_\_\_

Axis II: \_\_\_\_\_  
Descriptive Term Code

10. OTHER DISABILITIES

- 0 = No disability  
1 = Some disability  
2 = Major disability

- 10A. \_\_\_\_\_ Ambulation (Walking)  
10B. \_\_\_\_\_ Autism  
10C. \_\_\_\_\_ Behavior: Aggressive or Destructive  
10D. \_\_\_\_\_ Behavior: Self Abusive  
10E. \_\_\_\_\_ Brain Injury  
10F. \_\_\_\_\_ Cerebral Palsy  
10G. \_\_\_\_\_ Communication  
10H. \_\_\_\_\_ Dementia (Including Alzheimer's Disease)  
10I. \_\_\_\_\_ Health Problems (Major): \_\_\_\_\_  
10J. \_\_\_\_\_ Hearing  
10K. \_\_\_\_\_ Physical Disability Other Than Ambulation: \_\_\_\_\_  
10L. \_\_\_\_\_ Seizures  
10M. \_\_\_\_\_ Substance Abuse: \_\_\_\_\_  
10N. \_\_\_\_\_ Vision  
10O. \_\_\_\_\_ Other (s) \_\_\_\_\_

11. LEGAL STATUS

- 1 Parent or other relative is guardian  
2 Unrelated person is guardian  
3 No guardian

Living Situation and History

1. TYPE OF HOME:  
1 = Winfield State Hospital  
2 = Topeka State Hospital  
\_\_\_\_\_
2. WHEN DID THIS PERSON COME TO LIVE HERE? (MOST RECENT ADMISSION IF MORE THAN ONE.)  
\_\_\_\_\_  
Month      Year
3. WHAT IS THE PRIMARY REASON THE PERSON IS LIVING HERE?  
1 = Person or family chose this place  
2 = SRS chose this place  
3 = Court committed  
4 = Temporary placement  
5 = Other  
\_\_\_\_\_
4. HOW MANY PEOPLE LIVE IN THIS HOME? (Cottage or living unit or building or wing or other meaningful subunit if this is a State Hospital or other congregate facility.)  
\_\_\_\_\_ People in this home (or cottage or living unit etc.)
- 4A. \_\_\_\_\_ People with disabilities
- 4B. \_\_\_\_\_ People without disabilities (unpaid cohabitants)
- 4C. \_\_\_\_\_ Paid staff who live here
5. HOW MANY STAFF WORK AT THIS HOME? (Counting all shifts.)
- 5A. \_\_\_\_\_ Full Time Staff  
(Enter 0 if family home, independent living, etc.)
- 5B. \_\_\_\_\_ Part Time Staff  
(Enter 0 if family home, independent living, etc.)
6. WITH HOW MANY PEOPLE DOES THIS PERSON SHARE A BEDROOM?  
\_\_\_\_\_ People
7. HOW MANY TIMES IN THE PAST YEAR HAS THIS PERSON CHANGED HOMES?  
\_\_\_\_\_ times
8. WHAT KIND OF SETTING WAS THE PERSON LIVING IN BEFORE THIS ONE?  
\_\_\_\_\_
9. IF THERE HAVE BEEN MOVES, WHAT WAS THE MOST RECENT REASON?  
\_\_\_\_\_
10. ABOUT HOW MANY YEARS OF THIS PERSON'S LIFE HAVE BEEN SPENT IN INSTITUTIONAL OR CONGREGATE SETTINGS (STATE DEVELOPMENTAL CENTERS, ORPHANAGES, HOSPITALS, DETENTION CENTERS, PRISONS, ETC.)  
\_\_\_\_\_ Years (Enter 0 if none, 99 if Don't Know)

Daytime Activity Program, Work, and School

1. NAME OF PRIMARY DAYTIME ACTIVITY PROGRAM PROVIDER, JOB, OR SCHOOL:
  
2. HOURS PER WEEK OF DAYTIME ACTIVITIES, JOB, AND/OR SCHOOL:  
PLEASE ENTER THE NUMBER OF HOURS PER WEEK FOR EACH ACTIVITY.  
PLEASE ENTER 0 (ZERO) IF NO HOURS ARE SPENT IN THE CATEGORY.
  - 2A. \_\_\_\_\_ Self-Employed: Has His/Her Own Business
  - 2B. \_\_\_\_\_ Regular Job (Competitive Employment)
  - 2C. \_\_\_\_\_ Supported Employment  
(Regular job with supportive assistance at job site)
  - 2D. \_\_\_\_\_ Sheltered Employment  
(Work in a setting designed for people with disabilities)
  - 2E. \_\_\_\_\_ Vocational Rehabilitation or Training Day Program
  - 2F. \_\_\_\_\_ Adult Day Program - Non-Vocational Day Program
  - 2G. \_\_\_\_\_ Senior Citizen Program, Specialized
  - 2H. \_\_\_\_\_ Senior Citizen Program, Generic and Integrated
  - 2I. \_\_\_\_\_ Partial Hospitalization Program - Mental Health Oriented
  - 2J. \_\_\_\_\_ Volunteer Work
  - 2K. \_\_\_\_\_ Public School (Regular School Building and/or classroom)
  - 2L. \_\_\_\_\_ Public School (Separate Building or 'Center Based')
  - 2M. \_\_\_\_\_ Private School (Regular School Building and/or classroom)
  - 2N. \_\_\_\_\_ Private School (Separate Building or 'Center Based')
  - 2O. \_\_\_\_\_ Adult Education - GED, Adult Ed, Trade School, etc.
  - 2P. \_\_\_\_\_ Other \_\_\_\_\_
  - 2Q. \_\_\_\_\_ If Retired and no formal daytime activities, enter ZERO)
  - 2R. \_\_\_\_\_ If no activities (but not retired), enter ZERO
  
3. DURING DAY ACTIVITIES, WORK, OR SCHOOL, HOW MUCH TIME DOES THE PERSON SPEND IN THE PRESENCE OF THE PUBLIC? (Do not count during transportation.)
  - 1 = None or nearly none
  - 2 = Less than half the time
  - \_\_\_\_\_ 3 = About half the time
  - \_\_\_\_\_ 4 = More than half the time
  - \_\_\_\_\_ 5 = All or nearly all
  
4. DURING DAY ACTIVITIES, WORK, OR SCHOOL, HOW MUCH TIME DOES THE PERSON SPEND IN THE PRESENCE OF CO-WORKERS OR PEERS WHO DO NOT HAVE DISABILITIES? (Do not count during transportation.)
  - 1 = None or nearly none
  - 2 = Less than half the time
  - \_\_\_\_\_ 3 = About the time
  - \_\_\_\_\_ 4 = More than half the time
  - \_\_\_\_\_ 5 = All or nearly all
  
5. EARNINGS: ABOUT HOW MUCH DOES THIS PERSON EARN IN AN AVERAGE WEEK? (Accept per hour, biweekly, per month, or annual, and make notes in the margin if necessary. Convert to dollars per week when you can.)  
\_\_\_\_\_ Dollars per week

Individual Program Plan, Case Management,  
and Services/Supports

1. INDIVIDUAL PLAN: Does this person have a Support Plan, a Habilitation Plan, an Individual Program Plan or IPP, an Individual Habilitation Plan or IHP, or an MTP?  
 0 No  
 1 Yes  
 \_\_\_\_\_

2. PLAN DATE: When was this plan last approved and/or signed?

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 Month Year

3. HOW MANY PEOPLE ARE ON THE PERSON'S PLANNING TEAM?

\_\_\_\_\_ members

4. PLEASE CATEGORIZE THE TEAM MEMBERS:

	PAID	UNPAID
INVITED BY THE PERSON AND/OR THE PERSON'S CIRCLE OF FRIENDS	4A	4B
NOT INVITED BY THE PERSON AND/OR THE PERSON'S CIRCLE OF FRIENDS	4C	4D

5. TYPE OF PLAN: Was this plan the result of a person-centered planning process?

0 No  
 1 Yes  
 9 Unclear, not sure what person-centered planning means  
 \_\_\_\_\_

6. PRESENCE AT PLANNING PROCESS: Was the person present for his or her own Plan development and/or review?

0 No, presence was judged not appropriate because of behavioral, communication, or cognitive barriers [SKIP TO ITEM 7]  
 1 No, person chose not to be present [SKIP TO ITEM 7]  
 2 Yes, person was present for a small part of the process  
 3 Yes, person was present for most of all of the process  
 \_\_\_\_\_

7. PARTICIPATION IN PLANNING PROCESS: Did the person participate in his or her own Individual Plan development and/or review?

0 No, person was not able to participate  
 1 No, person chose not to participate  
 2 Yes, minimally  
 3 Yes, actively  
 \_\_\_\_\_

8. DOES THE PERSON'S INDIVIDUAL SUPPORT PROGRAM PLAN, HABILITATION PLAN, IPP, OR IHP HAVE A GOAL FOR MOVING TO A COMMUNITY HOME?

0 No  
 1 Yes  
 \_\_\_\_\_

9. NAME OF CASE MANAGER OR SUPPORT COORDINATOR:

\_\_\_\_\_

10. NUMBER OF CASE MANAGER OR SUPPORT COORDINATOR CONTACTS: About how many times in the past year has this person's Case Manager or Support Coordinator visited him/her or made contact by phone about him/her?

10A. \_\_\_\_\_ visits in past 12 months (enter D/K if don't know)

10B. \_\_\_\_\_ phone contacts in past 12 months (D/K if don't know)

11. MOST RECENT CASE MANAGER OR SUPPORT COORDINATOR VISIT: About how many days ago did the Case Manager or Support Coordinator last visit this person?

\_\_\_\_\_ days ago (enter N/A if no visit in the past year, or D/K)

12. RESPONDENT'S OPINION OF PLAN'S USEFULNESS: How useful is the person's Plan to you and other helpers in day to day work with him/her?

1 Not At All Useful - The Plan is pretty much just a piece of paper, and helpers rarely look at it

2 Not Very Useful

3 Somewhat Useful

4 Very Useful

5 Extremely Useful - It is the primary source of guidance for day-to-day work with this person

13. INDIVIDUAL GOALS: Please refer to the Support Plan, the Habilitation Plan, the IPP, or the IHP, and list the **five most important goals** in the current plan. The five are to be selected by the respondent. If there are fewer than five, list however many there are. Code each goal from the list on the following page. Also find out from the respondent whether each goal is being worked on currently, and whether there has been any progress in the past year.

Is This Goal Being Worked On Right Now?      Have You Seen Any Progress In The Past Year?

1 = Much Regression  
2 = Some Regression  
3 = No Change  
4 = Some Progress  
5 = Much Progress

0 = No  
1 = Partial  
2 = Fully

SHORT DESCRIPTION OF GOAL      CODE

13A. _____	_____	13F. _____	13K. _____
13B. _____	_____	13G. _____	13L. _____
13C. _____	_____	13H. _____	13M. _____
13D. _____	_____	13I. _____	13N. _____
13E. _____	_____	13J. _____	13O. _____

## CODES FOR PROGRAM GOALS

### GOALS CONCERNING INDEPENDENT LIVING AND SELF-CARE SKILLS:

- 01 Dressing skills
- 02 Toileting
- 03 Domestic activities (house cleaning, bedmaking, laundry)
- 04 Eating (self feeding, use of utensils, table manners, table setting, eating in restaurants, food preparation)
- 05 Bathing and/or washing
- 06 Grooming and other hygiene (toothbrushing, hair care, shaving, cosmetics, etc.)
- 07 Understanding and use of numbers
- 08 Use of money and purchasing
- 09 Telling time
- 10 Handling emergencies (fire precaution, first aid, telephone assistance)
- 11 Obtaining generic community services (how to obtain medical, religious, psychological, etc., services)
- 12 Mobility/Travel (getting around home, neighborhood, public transportation, etc.)
- 13 Personal health care (recognizing signs of illness, use of medications, nutrition, following Doctor's orders, attending to menstruation)
- 14 Use of telephone
- 19 Other independence goals

### GOALS CONCERNING DEVELOPMENT OF SENSORY, MOTOR, AND COMMUNICATION SKILLS

- 20 Vision: using glasses, correction of eye problems, etc.
- 21 Hearing: using hearing aid, correction of other ear problems, etc.
- 22 Ambulation improvement: using physical aids if necessary
- 23 Arm use and hand-eye coordination: ability to grasp, manipulate, use fine motor skills, use adaptive devices
- 24 Use of verbal language
- 25 Use of non-verbal communication: signing, gestures, making needs known, expression of feelings, etc.
- 26 Use of written language: reading, writing, signs, etc.
- 27 Sensory awareness: sensory stimulation, sensory integration, etc.
- 29 Other sensory, motor, or communication goals

### GOALS CONCERNING REDUCTION OF BEHAVIOR PROBLEMS

- 30 Reduction of physical violence
- 31 Reduction of hostility or threatening
- 32 Reduction of property damage
- 33 Reduction of behaviors that disrupt others' activities
- 34 Reduction of rebelliousness, resistance to rules, instructions, etc.
- 35 Reduction of running away
- 36 Reduction of theft, stealing, shoplifting
- 37 Reduction of lying, cheating, borrowing without asking
- 38 Reduction of physical violence to self
- 39 Reduction of stereotyped behavior, odd or repetitive mannerisms, eccentric habits or bizarre oral habits
- 40 Reduction of inappropriate verbalization or vocalization: loud, repetitive, profane, disruptive, annoying
- 41 Reduction of inappropriate interpersonal manners: rudeness, over-familiarity, annoying, etc.
- 42 Reduction of clothing problems: refuses to wear or removes inappropriately, tears or damages, etc.
- 43 Reduction of withdrawal: extreme inactivity, lethargy, shyness, etc.
- 44 Reduction of hyperactivity
- 45 Reduction of any kind of inappropriate sexual behaviors
- 46 Reduction of psychological disturbance
- 49 Use this code for any behavioral goal not in the list

### GOALS CONCERNING DEVELOPMENT OF SOCIAL SKILLS

- 50 Awareness of others
- 51 One-to-one interaction: conversation, appropriate behavior, etc.
- 52 Group interaction
- 53 Family interaction: with parents, siblings, other relatives
- 54 Manners, customs, politeness, etiquette
- 55 Civic and legal duties: laws, respect for rights of others
- 56 Sexual interaction
- 57 Awareness of property and ownership: learning "mine" and "yours" appropriately
- 58 Improve attention span
- 59 Other social goals

### GOALS CONCERNING WORKING

- 60 Learn the concept of working for pay
- 61 Increase motivation to work
- 62 Learn specific job skills
- 63 Achieve a new or better work placement
- 64 Learn job-seeking skills: learning where to look, applying, promptness, appropriate dress, interviewing, etc.
- 65 Learn how people are expected to relate to employers and co-workers
- 69 Other work goals

### GOALS CONCERNING EDUCATION

- 70 Improve motivation to participate and learn in school
- 71 Learn appropriate classroom behavior (be still, be quiet, pay attention, do assigned activities)
- 72 Be transferred to a more appropriate or more advanced or more normalizing school placement
- 73 Achieve mastery of specific academic skills-reading, writing, arithmetic
- 79 Other education goals

### GOALS CONCERNING USE OF LEISURE TIME

- 80 Learn to use television appropriately: selectively, proper times, etc.
- 81 Develop hobby(s) - arts, crafts, music, reading, games, collecting, etc.
- 82 Develop skills in sports/athletic activities: regular exercise, tennis, bowling, swimming, etc.
- 83 Learn to use community resources more independently: parks, pools, movies, theaters, museums, churches, etc.
- 84 Learn to plan excursions: day trips, vacations, etc.
- 89 Other leisure goals

- 99 Other goal not in above list

14. Services/Supports

**INSTRUCTIONS**

- o Minutes per day is only a rough estimate!!!
- o Most people are awake around 840 minutes per day, so be sure the minutes don't add more than that!
- o If the service is not received every day, make notes in the margin and figure out per day later.

	IS THIS Service Called for in the Person's Current Individual Plan or MTP?		ROUGHLY How Many Minutes Per Day of this Service Does the Person Actually Receive?
	ENTER 1 = YES 0 = NO		ENTER MINUTES (0 if none)
<u>BASIC SELF-CARE SKILLS TRAINING</u> . . . . .	. 1	_____	13 _____
Teaching, not just helping; include hygiene, dressing, eating, domestic skills			
<u>COMMUNITY SKILLS TRAINING</u> . . . . .	. 2	_____	14 _____
Shopping, use of identification, transportation, handling emergencies, etc.			
<u>APPROPRIATE SOCIAL BEHAVIOR TRAINING</u> . . . . .	. 3	_____	15 _____
Manners, interpersonal skills, etc.			
<u>COGNITIVE SKILLS TRAINING</u> . . . . .	. 4	_____	16 _____
Letters, numbers, shapes, colors, reading, writing, arithmetic			
<u>OCCUPATIONAL THERAPY</u> . . . . .	. 5	_____	17 _____
Delivered, designed, or supervised by an Occupational Therapist			
<u>PHYSICAL THERAPY</u> . . . . .	. 6	_____	18 _____
Delivered, designed, or supervised by a Physical Therapist			
<u>COMMUNICATION, SPEECH, &amp; HEARING THERAPY</u> . . . . .	. 7	_____	19 _____
Formal programs designed to improve communication abilities (devices included)			
<u>RECREATION TRAINING</u> . . . . .	. 8	_____	20 _____
Learning ways to use leisure time			
<u>PSYCHOTHERAPY OR COUNSELING</u> . . . . .	. 9	_____	21 _____
Delivered directly by a trained therapist			
<u>SEXUALITY EDUCATION, TRAINING, OR COUNSELING</u>	10	_____	22 _____
Teaching person how to make safe and rewarding choices			
<u>PROGRAMS TO REDUCE CHALLENGING BEHAVIOR</u> . . . . .	. 11	_____	23 _____
Systematic reinforcement programs of any kind			
<u>PERSONAL CARE ATTENDANT OR AIDE</u> . . . . .	. 12	_____	24 _____
Providing help with physical or other needs			



Mental Health and Crisis Intervention Supports

1. MENTAL HEALTH SERVICES/SUPPORTS: Has this person received mental health services or supports during the past year?
- 0 No
  - \_\_\_\_\_ 1 Yes, medications monitoring only
  - \_\_\_\_\_ 2 Yes, counseling or therapy or other

2. RESPONDENT OPINION: ON A SCALE FROM 0 TO 10, HOW WOULD YOU RATE THE QUALITY OF RECENT MENTAL HEALTH SERVICES/SUPPORTS? (N/A if not applicable; D/K if "Don't Know")
- \_\_\_\_\_ 0 1 2 3 4 5 6 7 8 9 10  
Very Poor Excellent

3. HOW MANY TIMES IN THE PAST YEAR (IF ANY) HAS THIS PERSON RECEIVED CRISIS INTERVENTION SUPPORTS? (N/A if not applicable; D/K if "Don't Know")

- \_\_\_\_\_ In-home crisis supports
- \_\_\_\_\_ Emergency room
- \_\_\_\_\_ Private agency, outpatient
- \_\_\_\_\_ Private agency, inpatient
- \_\_\_\_\_ State agency, outpatient
- \_\_\_\_\_ State agency, inpatient

4. RESPONDENT OPINION: ON A SCALE FROM 0 TO 10, HOW WOULD YOU RATE THE QUALITY OF THE MOST RECENT CRISIS INTERVENTION SUPPORTS? (N/A if "Not Applicable," D/K if "Don't Know")
- \_\_\_\_\_ 0 1 2 3 4 5 6 7 8 9 10  
Very Poor Excellent

Closest Relative/Friend/Guardian/Guardian-Advocate for Mail Survey

IN THE OPINION OF THE RESPONDENT, WHO IS THIS PERSON'S CLOSEST RELATIVE, FRIEND, GUARDIAN, OR GUARDIAN-ADVOCATE? WE WILL SEND A MAIL SURVEY TO THIS INDIVIDUAL EVERY YEAR. IF THERE IS NO ONE WE COULD OR SHOULD SEND A SURVEY TO, PLEASE "X" OUT THIS SECTION OF THE FORM. (NEVER INCLUDE RELATIVES WHO WANT NO CONTACT CONCERNING THEIR RELATIVE.)

1. \_\_\_\_\_  
Name(s) of Relative, Friend, Guardian, or Conservator
2. \_\_\_\_\_  
Relationship to the Person
3. \_\_\_\_\_  
Complete Mailing Address, Including Apartment #
4. \_\_\_\_\_ 5. \_\_\_\_\_ 6. \_\_\_\_\_  
City or Town State Zip Code
7. \_\_\_\_\_ 8. \_\_\_\_\_  
Telephone Number Language, if not English
9. About how often does this close relative / friend / guardian / guardian-advocate above see this person? (Accept times per week, or per month, and convert to approximate number of times per year.)  
\_\_\_\_\_ Times Per Year
10. About how many people in this person's life would you describe as "close friends"?  
\_\_\_\_\_ close friends
11. Of those close friends, how many are paid (residential staff, day program staff, case managers, nurses, job coaches, personal care attendants, etc.)?  
\_\_\_\_\_ of the close friends are paid
12. Of those close friends, how many have disabilities (MI included)?  
\_\_\_\_\_ of the close friends have disabilities (MI included)
13. Does this person have anything that could be called a "circle of friends" who assist in planning with and supporting him/her?  
0 No  
1 Yes  
\_\_\_\_\_
14. If Yes, how many people are in this "circle of friends"?  
\_\_\_\_\_ members in the circle (ENTER "N" IF N/A)

Instructions

1. This information is to be obtained BY INTERVIEW from the staff (or other) person who knows this individual best.
2. These items are generally in developmental sequence, from lowest to highest.
3. Please record the highest level of which the person is capable on each item.
4. Score only what the person DOES do, NOT what the person "can" do or "could" do or "is able to" do. We want no speculation - only observed, actual behaviors.
5. Give credit for a "typical" behavior, that is, behavior that is performed at least one-fourth (1/4) of the time during the past 4 weeks.
6. If this typical behavior is performed with VERBAL prompts, give credit (unless otherwise noted in the item).
7. Do not give credit for behaviors performed with PHYSICAL guidance (unless otherwise noted in the item).
8. On any item, a "99" can be entered if the item is not applicable (usually because of disabilities that are too severe), or if the person is too young, or if the person has never displayed the behavior. The "99" choice is specially noted on items that have most often been done this way in the past.

**ADAPTIVE BEHAVIOR**

**MOTOR DOMAIN**

- 1 Rolling and Sitting
  - 1 Does not lift head when lying on stomach
  - 2 Lifts head when lying on stomach
  - 3 Lifts head and chest using arm support when lying on stomach
  - 4 Rolls from side to side
  - \_\_\_\_\_ 5 Rolls from front to back only
  - 6 Rolls from front to back and back to front
  - 7 Maintains sitting position with minimal support for at least five (5) minutes
  - 8 Sits without support for at least five (5) minutes
  - 9 Assumes and maintains sitting position independently
- 2 Hand use (If person has use of one hand only, rate that hand)
  - 1 No functional use of the hand
  - 2 Uses raking motion or grasps with hand
  - \_\_\_\_\_ 3 Uses thumb and fingers of hand in opposition
  - 4 Uses the fingers independently of each other
- 3 Arm Use (If person has one arm or use of one arm only, rate the use of that arm)
  - 1 No functional use of arm
  - 2 Moves arm from shoulder but does not extend or flex arm (i.e., does not have control of elbow joint)
  - \_\_\_\_\_ 3 Partially extends arm
  - 4 Fully extends arm
- 4 Crawling and Standing
  - 1 Does not crawl, creep, or scoot
  - 2 Crawls, creeps, or scoots
  - \_\_\_\_\_ 3 Pulls to a standing position
  - 4 Stands with support for at least one (1) minute
  - 5 Stands unsteadily alone for at least one (1) minute
  - 6 Stands well alone, balances well for at least five (5) minutes

- 5 Ambulation
- 1 Does not walk
  - 2 Walks with support
  - \_\_\_\_\_ 3 Walks unsteadily alone at least ten (10) feet
  - 4 Walks well alone at least twenty (20) feet, balances well
- 6 Climbing Stairs (Rate use of ramps for people using wheelchairs)
- 1 Does not move up or down stairs (or ramps)
  - 2 Moves up and down stairs (or ramps) with help
  - \_\_\_\_\_ 3 Moves up and down stairs (or ramps) with handrail independently
  - 4 Moves up and down stairs (or ramps) without need for handrail
- 7 Wheelchair Mobility
- 99 Does not use wheelchair (R4)
  - 1 Sits in wheelchair, does not move wheelchair by self
  - \_\_\_\_\_ 2 Assists in moving wheelchair
  - 3 Moves self with some bumping and/or difficulty in steering
  - 4 Moves or guides chair independently and smoothly

#### INDEPENDENT LIVING DOMAIN

- 8 Food preparation
- 99 Person is in a service setting in which he/she is prevented from preparing food (R1)
  - 1 Does not prepare food
  - \_\_\_\_\_ 2 Prepares simple foods without cooking (sandwich, cold cereal, etc.)
  - 3 Cooks simple foods (eggs, soup, frozen dinners, etc.)
  - 4 Cooks more complex foods and/or prepares complete meal
- 9 Bedmaking
- 99 Person is in a service setting in which he/she is prevented from bedmaking (R1)
  - 1 Does not make bed
  - \_\_\_\_\_ 2 Attempts bedmaking, but does not complete
  - 3 Makes bed completely, but not neatly (sheets and blankets appear wrinkled, bedspread crooked, etc.)
  - 4 Completes bedmaking neatly and independently
- 10 Washing dishes (Including dishwashing machine)
- 99 Person is in a service setting in which he/she is prevented from dishwashing (R1)
  - 1 Does not wash dishes
  - \_\_\_\_\_ 2 Attempts dishwashing, but does not complete
  - 3 Completes dishwashing, but with unacceptable results (water left on counter or floor, dishes chipped, etc.)
  - 4 Completes dishwashing neatly and independently
- 11 Household Chores (Other than food preparation, bedmaking, washing dishes)
- 99 Person is in a service setting in which he/she is prevented from doing household chores (R1)
  - 1 Does not do household chores
  - \_\_\_\_\_ 2 Attempts household chores but does not complete
  - 3 Does household chores, but not neatly (leaves dirt on the floor, spills garbage, etc.)
  - 4 Completes household chores neatly and independently
- 12 Basic Medical Self-Help (First aid, non-prescription medication)
- 99 Person is in a service setting in which he/she is prevented from performing basic medical self-help skills (R1)
  - 1 Does not display any medical self-help skills
  - \_\_\_\_\_ 2 Seeks aid in treatment of minor injuries
  - 3 Performs simple first aid tasks (applies bandages, ice to a burn)
  - 4 Has basic medical self-help skills and uses non-prescription medications (aspirins, cough drops, etc.) appropriately

- 13 Self Medication  
 99 Does not require any routine prescription medication or is in a service setting in which he/she is prevented from self-medication (R1)  
 1 Does not take any medication by self  
 2 Takes own medication with supervision and/or assistance  
 3 Takes own medication if reminded of time and/or dosage  
 4 Independently takes own medication as prescribed
- 14 Eating  
 1 Does not eat independently, must be fed completely  
 2 Attempts to finger feed, but needs assistance  
 3 Eats finger food without assistance  
 4 Eats using spoon, with spillage  
 5 Eats using fork and spoon, with spillage  
 6 Uses eating utensils with no spillage
- 15 Toileting  
 1 Not toilet trained or habit trained  
 2 Is habit trained  
 3 Indicates need to toilet self but needs major assistance to complete toileting  
 4 Goes to toilet by self, needs minor assistance to complete toileting  
 5 Goes to toilet by self, completes by self
- 16 Level of Bladder Control  
 1 No control  
 2 Some bladder control, accidents during waking hours (once a week or more)  
 3 Control during day, wets at night  
 4 Complete control
- 17 Level of Bowel Control  
 1 No control  
 2 Some bowel control, accidents during waking hours (once a week or more)  
 3 Control during day, soils at night  
 4 Complete control
- 18 Personal Hygiene (Brushing teeth, washing, and behaviors specifically related to gender and age, e.g., shaving, hair care, menses, use of deodorant)  
 1 Does not tend to own personal hygiene  
 2 Tends to some personal hygiene, but does not complete  
 3 Tends to and completes some but not all personal hygiene tasks  
 4 Tends to own personal hygiene independently
- 19 Bathing  
 1 Does not bathe or shower self  
 2 Performs some bathing or showering tasks, but not all  
 3 Bathes or showers self independently
- 20 Dressing  
 1 Does not put on any clothing by self  
 2 Cooperates in putting on clothes (raises arms, etc.)  
 3 Puts on some clothing by self  
 4 Puts on all clothes but does not tie shoes, close all fasteners or attend to other details  
 5 Dresses self completely including all fasteners and other details (buttons, zippers, shoes)

- 21 Movement in Familiar Setting
- 1 Does not move about in a familiar setting
  - \_\_\_\_\_ 2 Moves about in a familiar setting but does not successfully move around obstructions or from room to room
  - 3 Moves about in a familiar setting and successfully moves around objects but has difficulty going from room to room
  - 4 Knows way around and moves about successfully in a familiar setting
- 22 Movement in Unfamiliar Settings
- 1 Does not move about unfamiliar setting
  - \_\_\_\_\_ 2 Moves about in unfamiliar setting but does not successfully move around obstructions or from place to place
  - 3 Moves about in unfamiliar setting and successfully moves around objects but has difficulty going from place to place
  - 4 Finds way around and moves about successfully in unfamiliar setting
- 23 Transportation About Community
- 99 No public transportation available (R1)
  - 1 Does not use public transportation
  - 2 Uses public transportation with physical assistance and/or accompaniment
  - \_\_\_\_\_ 3 Uses public transportation independently for a simple direct trip
  - 4 Uses public transportation independently for a complex route
- 24 Money Handling
- 1 Does not use money
  - 2 Uses money but is unable to provide appropriate amount (gives 10 cents to purchase any item in store, etc.)
  - \_\_\_\_\_ 3 Uses money, but does not usually make and/or count change correctly
  - 4 Adds coins of various denominations, makes and/or counts change to \$1
  - 5 Makes and/or counts change in any amount
- 25 Purchasing
- 1 Does not make purchases
  - 2 Identifies items desired to purchase, but does not make purchase
  - \_\_\_\_\_ 3 Manages purchases with some difficulty
  - 4 Manages purchases independently
- 26 Ordering Food in Public (Including with visual aids)
- 1 Does not order food at public eating places
  - \_\_\_\_\_ 2 Orders snacks (ice cream, hot dogs, tacos, etc.)
  - 3 Orders simple meals (hamburgers and fries, tacos and beans, etc.), may require assistance
  - 4 Orders complete meals independently

**SOCIAL DOMAIN**

- 27 One-to-One Interaction with Peers (friends, classmates, co-workers, etc.)
- 1 Does not enter into interaction
  - 2 Enters into interaction only when others initiate
  - \_\_\_\_\_ 3 Initiates interaction in familiar or previously successful situations or settings
  - 4 Initiates interaction in both familiar and unfamiliar situations or settings
- 28 One-to-One Interaction with Persons Other than Peers (store clerks, foster parents, teachers, bus drivers, etc.)
- 1 Does not enter into interaction
  - 2 Enters into interaction only when others initiate
  - \_\_\_\_\_ 3 Initiates interaction in familiar or previously successful situation or settings
  - 4 Initiates interaction in both familiar and unfamiliar situations or settings

- 29 Friendship Formation (Close social relationships)
- 1 Does not form friendships
  - 2 Potential friends must initiate friendships
  - 3 Initiates and establishes friendships
- 
- 30 Friendship Maintenance (For at least three months)
- 1 Does not maintain friendships
  - 2 Maintains friendships only in stable or familiar settings (classroom, residence, etc.)
  - 3 Maintains friendships in many different settings
- 31 Appropriate Sexual Caution With Others
- 99 Person is not sexually active with others (R4)
  - 1 Takes no precautions, not aware of risks
  - 2 At least somewhat aware of risks, but unreliable about precautions
  - 3 Aware of risks, and usually takes appropriate precautions
  - 4 Reliably cautious
- 
- 32 Participation in Social Activities
- 1 Does not participate in social activities
  - 2 Participates in social activities only with considerable encouragement
  - 3 Participates in social activities with some encouragement
  - 4 Does not need encouragement to participate in social activities
- 
- 33 Participation in Group Projects
- 1 Does not participate in group projects
  - 2 Participates in group projects but efforts do not contribute to group effort
  - 3 Participates in group projects but efforts only partially contribute to group effort
  - 4 Participates in group projects and efforts contribute to the completion of the projects

#### ADJUSTMENT DOMAIN

- 34 Adjustment to Changes in Social Relationships (e.g., change of caregiver, disruption of friendship group)
- 99 Person is too disabled to display this type of behavior (R3)
  - 1 Changes in social relationships cause disruption of typical functioning which extends over at least a 3 month period
  - 2 Changes in social relationships cause disruption of typical functioning but there is improvement within one month
  - 3 Changes in social relationships do not appear to disrupt typical functioning
  - 4 Changes in social relationships appear to lead to improvement and personal growth
- 
- 35 Adjustment to Changes in Physical Environment
- 99 Person is too disabled to display this type of behavior (R3)
  - 1 Changes in physical environment cause disruption of typical functioning which extends over at least a 3-month period
  - 2 Changes in physical environment cause disruption of typical functioning but there is improvement within one month
  - 3 Changes in physical environment do not appear to disrupt typical functioning
  - 4 Changes in physical environment appear to lead to improvement and personal growth

## COGNITIVE DOMAIN

- 36 Auditory Perception (Hearing aid may be worn)
- 1 Does not react to sound
  - 2 Demonstrates startle response
  - 3 Turns head or eyes toward sound source
  - \_\_\_\_\_ 4 Responds differently to voices compared to other sounds (by smiling or paying attention to the voices)
  - 5 Responds to voices of familiar people differently from strangers' voices
  - 6 Recognizes words that sound different ("cat" and "door")
  - 7 Recognizes words that sound the same ("hit" and "sit")
- 37 Visual Perception (Glasses may be worn)
- 1 Does not explore visually (includes continuous staring)
  - 2 Some visual exploration, but does not follow moving objects
  - 3 Eyes follow moving objects
  - \_\_\_\_\_ 4 Rotates head and inspects surroundings (if no motor limitations)
  - 5 Searches for object which disappears from sight
  - 6 Responds differently to grossly different objects (a ball and a pencil)
  - 7 Responds differently to similar objects (a cat and a dog)
  - 8 Responds differently to objects based on differences of color, size or shape
- 38 Associating Time with Events and Actions
- 1 Does not associate events and actions with time
  - 2 Associates regular events with morning, noon, or night
  - \_\_\_\_\_ 3 Associates regular events with a specific hour (dinner is at six)
  - 4 Associates events with specific time in past, present and future (the ball game is at six tomorrow)
- 39 Number Awareness
- 1 Does not count
  - 2 Counts, but inaccurately or by rote
  - \_\_\_\_\_ 3 Counts to 10 and associates single digit numbers with quantities
  - 4 Counts to 10 and understands relative values (8 is larger than 3)
  - 5 Counts, includes use of multi-digit numbers, and associates multi-digit numbers with quantities
- 40 Writing Skills (Including Braille and typing)
- 1 Does not copy or trace
  - 2 Copies from model or traces
  - \_\_\_\_\_ 3 Prints (no model) single letters or name only
  - 4 Prints single words only
  - 5 Prints words and sentences legibly
  - 6 Uses longhand for words and sentences
- 41 Reading Skills (Including Braille)
- 1 Does not read
  - 2 Recognizes single letters
  - \_\_\_\_\_ 3 Reads simple words but does not comprehend
  - 4 Reads and comprehends simple words
  - 5 Reads and comprehends simple sentences
  - 6 Reads and comprehends complex sentences and stories
- 42 Attention Span
- 1 Does not keep attention focused on a single purposeful activity
  - 2 Keeps attention focused on a single purposeful activity for less than one minute
  - \_\_\_\_\_ 3 Keeps attention focused on a single purposeful activity between one and five minutes
  - 4 Keeps attention focused on a single purposeful activity between five and fifteen minutes
  - 5 Keeps attention focused on a single purposeful activity fifteen minutes or more



- 43 Safety Awareness (Following safety rules and avoiding hazardous situations)
- 1 Frequently endangers self, must be supervised at all times
  - 2 Occasionally endangers self, requires supervision on a daily basis
  - 3 Endangers self only in unfamiliar situation or settings
  - 4 Typically does not endanger self
- 44 Remembering Instructions and Demonstrations
- 1 Does not display memory of instructions or demonstrations
  - 2 Displays memory of instructions or demonstrations if they are repeated three or more times and the person is prompted to recall
  - 3 Displays memory of instructions or demonstrations if they are given once and the person is prompted to recall
  - 4 Displays memory of instructions or demonstrations without prompting if they are given once

#### COMMUNICATION DOMAIN

- 45 Word Usage
- 1 No use of words
  - 2 Uses simple (one-syllable) words and associates words with appropriate objects
  - 3 Uses complex words and associates words with appropriate objects, but has limited vocabulary
  - 4 Has a broad vocabulary, understands meaning of words and uses them in appropriate contexts
- 46 Expressive Nonverbal Communication  
(Not including sign language or communication aids)  
(Note: Verbal people should almost always score a "4" here - R4)
- 1 No expressive nonverbal communication
  - 2 Expresses needs or reactions by squirming, returning smiles, etc.
  - 3 Communicates by pointing, shaking head, leading by the hand, etc.
  - 4 Gestures with hands, uses facial expressions for communication
- 47 Receptive Nonverbal Communication  
(Not including sign language -R4)
- 1 Does not demonstrate understanding of gestures (tactile or visual) or facial expressions
  - 2 Demonstrates understanding of simple gestures ("yes," "no," pointing to an object)
  - 3 Demonstrates understanding of complex gestures
  - 4 Demonstrates understanding of a series of gestures (tactile or visual)
- 48 Receptive Language
- 1 Does not understand speech
  - 2 Understands simple words
  - 3 Understands simple phrases or instructions
  - 4 Understands meaning of simple conversation and combination of verbal instructions
  - 5 Understands meaning of story plot and complex conversation
- 49 Expressive Language
- 1 Makes no sounds
  - 2 Babbles but says no words
  - 3 Says simple words
  - 4 Says two-word sentences ("I go," "Give me," etc.)
  - 5 Says sentences of three or more words
  - 6 Carries on basic conversation
  - 7 Carries on more complex conversation

- 50 Receptive Sign Language
- 99 Skills not needed (R5)
  - 1 Does not respond to signs or finger spelling
  - 2 Responds to one to nine signed basic survival words (stop, restroom, come, etc.) as well as other common signs (simple commands, food, clothing, etc.)
  - \_\_\_\_\_ 3 Responds to signed complex commands made up of two or more parts ("Go to the bathroom and bring me a towel")
  - 4 Responds to signed complex commands, directions and explanations with a combination of signs and simple finger spelling
  - 5 Responds to signed questions (3 or more words) with a combination of signs and finger spelling
- 51 Expressive Sign Language
- 99 Skills not needed (R7)
  - 1 Does not sign or imitate signs
  - 2 Imitates sign language but makes no meaningful signs
  - 3 Makes one to nine signs independently to indicate a need
  - \_\_\_\_\_ 4 Makes ten or more signs independently to indicate needs
  - 5 Makes twenty or more signs independently to indicate needs and/or simple conversation
  - 6 Makes fifty or more signs, finger spells simple words and makes simple sentences
  - 7 Signs and finger spells independently in carrying on conversations as well as expressing needs
- 52 Expressive Communication with Aids (Includes all types of specialized devices which allow or facilitate communication)
- 99 Aids not needed (R4)
  - 1 Does not communicate with aids
  - \_\_\_\_\_ 2 Communicates single words or ideas
  - 3 Forms short sentences; combines subject and verb
  - 4 Communicates combinations of sentences and groups of ideas together
- 53 Clarity of Speech
- 1 Makes no sounds
  - 2 No intelligible speech
  - \_\_\_\_\_ 3 Speech understood only by those who know the person well
  - 4 Speech understood by strangers with some difficulty
  - 5 Speech is readily understandable to a stranger

### PRODUCTIVE ACTIVITIES

(WORK, HOUSEHOLD CHORES, VOLUNTEERING, SCHOOL OR OTHER EDUCATION, SERIOUS HOBBIES, EXERCISE PROGRAMS, ETC.)

- 1 Motivation for Productive Activities
- 0 No evidence of motivation, willingness, or interest in doing things usually called "productive" as above
  - 1 Will engage in productive activities only with constant supervision and/or encouragement
  - \_\_\_\_\_ 2 Some motivation for productive activities
  - 3 Moderate motivation for productive activities
  - 4 Strong motivation for productive activities
  - 5 Enthusiastic about work and productive activities
- 2 Getting Up in the Morning
- 0 Completely dependent, must be awakened and assisted
  - 1 Uncooperative about getting up in the morning
  - 2 Cooperative about getting up, but must be awakened
  - \_\_\_\_\_ 3 Awakens by self, but not reliably
  - 4 Awakens by self, reliably, but not always on time
  - 5 Completely independent and reliable about getting up on time

- 3 Working With Others
- 0 Does not work with others
  - 1 Has considerable difficulty working with others, but performs with close supervision
  - \_\_\_\_\_ 2 Works well with others with general supervision
  - 3 Works well with others, requires only minimal supervision
- 4 Organization
- 0 Does not organize at work or other productive activities
  - 1 Organizes work only with close supervision
  - \_\_\_\_\_ 2 Organizes work with general supervision
  - 3 Organizes work well with minimal supervision
- 5 Following Safety Rules and Regulations When Doing Work or Other Productive Activities
- 0 Shows no awareness of, nor compliance with, safety rules and regulations
  - 1 Complies with safety rules and regulations only with close supervision
  - \_\_\_\_\_ 2 Complies with safety rules and regulations with general supervision
  - 3 Complies with safety rules and regulations with minimal or no supervision
- 6 Quality of Work or Other Productive Activities
- 0 Quality of work is usually poor, even with close supervision
  - 1 Quality of work is usually fair, with close supervision
  - \_\_\_\_\_ 2 Quality of work is usually good, with close supervision
  - 3 Quality of work is usually good, with general supervision
  - 4 Quality of work is usually excellent, with minimal or no supervision
- 7 Keeping A Job
- 0 Does not keep a job, or does not work
  - 1 Has a history of quitting or being let go after a few days or weeks
  - \_\_\_\_\_ 2 Has kept a job for as long as a month
  - 3 Has kept a job for as long as 6 months
  - 4 Has kept a job for as long as a year
  - 5 Has kept a job for a long period, over a year
  - 6 Has a long term career with stability
- 8 Promptness and Attendance at Job or Day Program  
(Enter N/A if Not Applicable)
- 0 Frequently unreliable about getting to work on time or frequently no-shows
  - 1 Often unreliable about promptness or attendance
  - \_\_\_\_\_ 2 Usually reliable about promptness or attendance
  - 3 Always or almost always reliable
- 9 Getting to Work or Day Program
- 0 Completely dependent on others to get to work or day program
  - 1 Largely dependent on others, but does assist with parts of the routine
  - \_\_\_\_\_ 2 Partly dependent on others, but does some part of the travel independently
  - 3 Gets to work or day program with minor assistance such as verbal reminders
  - 4 Gets to work or day program independently and reliably
- 10 Advancement (promotions, raises, titles, more demanding roles)
- 0 Has never advanced at day program or job
  - 1 Has received promotions or raises, but not in the past year
  - \_\_\_\_\_ 2 Has advanced once in a day program or job in the past year
  - 3 Has advanced twice in the past year
  - 4 Has advanced three or more times in the past year

## CHALLENGING BEHAVIORS

- 1 Unacceptable Social Behavior (Stealing, excessive screaming, lying, teasing, etc.)
  - 1 Unacceptable social behaviors prevent social participation
  - 2 Unacceptable social behaviors often disrupt social participation
  - 3 Unacceptable social behaviors seldom interfere with social participation
  - 4 Unacceptable social behaviors do not occur or do not interfere with social participation
- 2 Aggression
  - 1 Has had one or more violent episodes, causing serious physical injury within past year
  - 2 Has had one or more violent episodes, causing minor physical injury within past year
  - 3 Resorting to verbal abuse and threats are typical of person's behavior but person has not caused physical injury within past year
  - 4 Episodes of displaying anger are undetected or rare and appropriate to the situation
- 3 Frequency of Self-Injurious Behavior (Biting, scratching, putting inappropriate objects into ear, mouth, etc.)
  - 1 Displays self-injurious behavior at least once a day and/or restraints are used as a preventative measure
  - 2 Displays self-injurious behavior at least once a week
  - 3 Displays self-injurious behavior at least once a month
  - 4 Displays self-injurious behavior not more than three (3) times a year
  - 5 Rarely or never displays self-injurious behavior
- 4 Severity of Self-Injurious Behavior (Biting, scratching, putting inappropriate objects into ear, mouth, etc.)
  - 1 Self-injurious behavior causes severe injury at least once per week which requires a physician's attention
  - 2 Self-injurious behavior causes severe injury at least once a month which requires physician's attention and/or injury at least once per week which requires first aid
  - 3 Self-injurious behavior causes severe injury at least once a year which requires physician's attention and/or minor injury at least once per month which requires first aid
  - 4 Behavior exists but no apparent injury occurs
  - 5 Rarely or never displays self-injurious behavior
- 5 Unsanitary behavior with feces or urine
  - 1 Unsanitary at every opportunity unless prevented
  - 2 Unsanitary more than once per week
  - 3 Unsanitary more than once per month
  - 4 Unsanitary very seldom, less than once per month
  - 5 Never unsanitary
- 6 Destruction of Property
  - 1 Has caused serious property damage (more than \$50) on one or more occasions within the past year
  - 2 Has caused minor property damage (less than \$50) on six (6) or more occasions within the past year
  - 3 Has caused minor property damage on two (2) to five (5) occasions within the past year
  - 4 Has caused minor property damage once during the past year
  - 5 Does not damage property

- 7 Running or Wandering Away
- 1 Running or wandering away occurs daily unless prevented
  - 2 Running or wandering away occurs weekly but not daily unless prevented
  - 3 Running or wandering away occurs at least once a month
  - 4 Running or wandering away occurs at least once every three months
  - 5 Running or wandering away occurs at least once a year
  - 6 Running or wandering away is threatened, but not attempted
  - 7 Does not run or wander away
- 8 Depressive-like Behavior (Listlessness, excessive crying and weeping, suicidal threats, etc.)
- 99 Person is too young or too disabled to display this type of behavior (R4)
  - 1 Depressive-like behavior inhibits all functions (prevents interaction with others, interferes with daily activities, etc.)
  - 2 Depressive-like behavior substantially affects all functions (limits communication and typical performance in daily activities, etc.)
  - 3 Depressive-like behavior has minimal effect on functioning (attends to daily activities with slight decrease in performance, etc.)
  - 4 No evidence of depressive-like behavior (maintains typical daily activities, etc.)
- 9 Reaction to Frustration
- 99 Person is too young or too disabled to display this type of behavior (R4)
  - 1 Becomes aggressive or hostile in most daily situations when thwarted, hindered or obstructed
  - 2 Becomes aggressive, hostile at least once a week when thwarted, hindered or obstructed
  - 3 Becomes aggressive, hostile less often than once a week when thwarted, hindered or obstructed
  - 4 Deals effectively with frustrating situations; rarely becomes aggressive or hostile when thwarted, hindered or obstructed
- 10 Repetitive Body Movements (Hand flapping, rocking and other stereotypical behaviors)
- 99 Person is too young or too disabled to display this type of behavior (R5)
  - 1 Repetitive body movements occur continuously (without cessation during waking hours)
  - 2 Repetitive body movements occur continuously but person can be distracted from behavior (when attending to task, etc.)
  - 3 Some repetitive body movements occur daily regardless of situation
  - 4 Repetitive body movements occur only under conditions of excitement and/or stress
  - 5 No apparent repetitive body movements
- 11 Inappropriate Undressing
- 99 Person is too young or too disabled to display this type of behavior (R4)
  - 1 Undresses self inappropriately in shopping centers, playgrounds, schoolrooms, etc.
  - 2 Undresses self in residence inappropriately more than once per week
  - 3 Undresses self in residence inappropriately, not more than once per week
  - 4 Does not undress self inappropriately

- 12 Hyperactivity (As manifested by over-excitability, restlessness, constant movement; exclude spastic movements)
- 99 Person is too disabled to display this type of behavior (R5)
- 1 Is hyperactive in all environments even with individual attention (one-to-one supervision)
- 2 Is hyperactive except when given individual attention (one-to-one supervision)
- 3 Is hyperactive only in stressful situations (when in groups of unfamiliar people, when being reprimanded, etc.); hyperactivity is otherwise controlled by behavior modification techniques and/or medication
- 4 Hyperactivity is controlled by behavior modification techniques and/or medication
- 5 No apparent hyperactivity
- 13 Temper Tantrums (Emotional outbursts)
- 99 Person is too disabled to display this type of behavior (R5)
- 1 Typically displays temper tantrums daily
- 2 Typically displays temper tantrums at least once a week but not daily
- 3 Typically displays temper tantrums at least once a month but not weekly
- 4 Displays temper tantrums not more than three (3) times a year
- 5 Does not display temper tantrums
- 14 Resistiveness (Inappropriately stubborn and uncooperative)
- 99 Person is too young or too disabled to display this type of behavior (R4)
- 1 Is resistive in all situations
- 2 Is resistive in one or more situations
- 3 Is resistive *only* in stressful situations (when in groups of unfamiliar people, when being reprimanded, etc.)
- 4 Is not resistive
- 15 Socially Inappropriate Sexual Behavior (any behaviors, heterosexual or homosexual or self-directed, that are socially unacceptable, e.g., forcible advances, public exposure, etc.)
- 99 Person exhibits no sexuality (R4)
- 1 Extremely urgent problems that may be illegal
- 2 Serious problems that require major attention and/or intervention
- 3 Minor problems that require minor attention and/or intervention
- 4 No problems in this area

# Decision Control Inventory

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Ask the respondent to select a number from 0 to 10 to show who actually makes decisions in each area. If decisions are made entirely by PAID PERSONNEL (the respondent, other program staff, Case Manager, agency officials, doctors, etc.), enter "0" for that area. If decisions are made entirely by the PERSON AND/OR UNPAID FAMILY, FRIENDS, ADVOCATES, etc., enter "10." If decisions are equally shared, enter "5."

0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10  
PAID STAFF PERSON AND/OR UNPAID FRIENDS, RELATIVES, etc.

## FOOD

- \_\_\_\_\_ 1. What foods to buy for the home when shopping
- \_\_\_\_\_ 2. What to have for breakfast
- \_\_\_\_\_ 3. What to have for dinner
- \_\_\_\_\_ 4. Choosing restaurants when eating out

## CLOTHES AND GROOMING

- \_\_\_\_\_ 5. What clothes to buy in store
- \_\_\_\_\_ 6. What clothes to wear on weekdays
- \_\_\_\_\_ 7. What clothes to wear on weekends
- \_\_\_\_\_ 8. Time and frequency of bathing or showering

## SLEEP AND WAKING

- \_\_\_\_\_ 9. When to go to bed on weekdays
- \_\_\_\_\_ 10. When to go to bed on weekends
- \_\_\_\_\_ 11. When to get up on weekends
- \_\_\_\_\_ 12. Taking naps in evenings and on weekends

## RECREATION

- \_\_\_\_\_ 13. Choice of places to go
- \_\_\_\_\_ 14. What to do with relaxation time, such as what to watch on TV, what music to listen to, books to read
- \_\_\_\_\_ 15. Visiting with friends outside the person's residence
- \_\_\_\_\_ 16. Choosing to decline to take part in group activities

## SUPPORT AGENCIES AND STAFF

- \_\_\_\_\_ 17. Choice of which service agency works with person
- \_\_\_\_\_ 18. Choice of Case Manager
- \_\_\_\_\_ 19. Choice of agency's support persons/staff (N/A if family)

## HOME

- \_\_\_\_\_ 20. Choice of house or apartment
- \_\_\_\_\_ 21. Choice of people to live with
- \_\_\_\_\_ 22. Choice of furnishings and decorations in the home

## WORK OR OTHER DAY ACTIVITIES

- \_\_\_\_\_ 23. Type of work or day program
- \_\_\_\_\_ 24. Amount of time spent working or at day program
- \_\_\_\_\_ 25. Type of transportation to and from day program or job

## OTHER

- \_\_\_\_\_ 26. What to do with personal money
- \_\_\_\_\_ 27. Express affection, including sexual
- \_\_\_\_\_ 28. "Minor vices" - use of tobacco, alcohol, caffeine, explicit magazines, etc.
- \_\_\_\_\_ 29. Whether to have pet(s) in the home

Integrative Activities During the Past Month

ABOUT HOW MANY TIMES did this person do each of the following in the PAST MONTH? ONLY COUNT ACTIVITIES WHEN THE PERSON WAS IN THE PRESENCE OF NON-DISABLED CITIZENS. (Rough estimates are fine. If the past month was not typical, ask about the average month during the past year. Write DK if "Don't Know.")

1. \_\_\_\_\_ Visit with close friends, relatives or neighbors
2. \_\_\_\_\_ Visit a grocery store
3. \_\_\_\_\_ Go to a restaurant
4. \_\_\_\_\_ Go to church or synagogue
5. \_\_\_\_\_ Go to a shopping center, mall or other retail store to shop
6. \_\_\_\_\_ Go to bars, taverns, etc.
7. \_\_\_\_\_ Go to a bank
8. \_\_\_\_\_ Go to a movie
9. \_\_\_\_\_ Go to a park or playground
10. \_\_\_\_\_ Go to a theater or cultural event  
(including local school or club productions and events)
11. \_\_\_\_\_ Go to a post office
12. \_\_\_\_\_ Go to a library
13. \_\_\_\_\_ Go to a sports event
14. \_\_\_\_\_ Go to a health or exercise club, spa, or center
15. \_\_\_\_\_ Use public transportation (May be marked "N/A")
16. \_\_\_\_\_ Other kind of "getting out" not listed above
  
17. When the person goes out, about how much of the time is it:  
\_\_\_\_\_ % with no other people with disabilities  
(alone or with staff, relatives, friends, if needed)  
\_\_\_\_\_ % with one other person with disabilities  
(plus staff, relatives, or friends, if needed)  
\_\_\_\_\_ % with more than one other people with disabilities  
(plus staff, relatives, or friends, if needed)  
100 % (total should be 100%)



Legal Concerns

1. Has this person ever had any involvement with the criminal justice system (arrests, taken into custody by police, investigations, etc.) IF NO, PLEASE SKIP TO QUESTION 5

0 No  
1 Yes

\_\_\_\_\_

2. If Yes, when was the last time?

\_\_\_\_\_ Year

3. How many times, if any, has this person ever been in prison?

\_\_\_\_\_ Times

4. If the person has been in prison, when was the last time released?

\_\_\_\_\_ Year

5. ALLEGED ILLEGAL BEHAVIORS

0=No

1=Yes, but not in the past year

2=Yes, within the past year

5A. \_\_\_\_\_ Stealing, theft, or shoplifting

5B. \_\_\_\_\_ Assault that could result in serious injury to another

5C. \_\_\_\_\_ Attempted suicide

5D. \_\_\_\_\_ Vandalism, or any serious property destruction (over \$100)

5E. \_\_\_\_\_ Sexual acts that are illegal (e.g., prostitution, exhibitionism, child molestation, rape, etc.)

5F. \_\_\_\_\_ Substance abuse, purchase, or sale

5G. \_\_\_\_\_ Fire setting

\_\_\_\_\_ Other illegal acts \_\_\_\_\_

Questions To Be Asked of the Respondent Who Knows the Person Best

1. How long have you been working with this person?

\_\_\_\_\_ Years and \_\_\_\_\_ Months

2. How long have you been working in this field (mental retardation, developmental disabilities, mental health)?

\_\_\_\_\_ Years and \_\_\_\_\_ Months

3. How much do you like this job, on a scale of 0 to 10? (0 means not liking the job at all, and 10 means liking it a lot.)

\_\_\_\_\_

4. How much did you like this job when you first started? (0 to 10.)

\_\_\_\_\_

5. How do you feel about working with this person specifically, on a scale from 0 to 10? (0 means very negative, and 10 means very positive.)

\_\_\_\_\_

6. What three words come to mind when you think about this person?  
**NOTE: Accept one, two, or three words.**

\_\_\_\_\_

7. If you could have one wish granted for this person, what would you wish for?

8. Do you work here part time or full time?

\_\_\_\_\_ 1 = Part Time  
2 = Full Time

9. What kinds of training have you had for this job?  
(CHECK OFF WHICH ONES, AND THEN ENTER ABOUT HOW MANY HOURS OF EACH KIND OF TRAINING IN THE PAST YEAR.)

- 9.1  General orientation to the job (before the job started)
- 9.2  Introductory training about psychiatric disabilities
- 9.3  Introductory training about mental retardation
- 9.4  Homemaker training
- 9.5  Goal planning / IPPs / ID Team process
- 9.6  First Aid training
- 9.7  Medications training
- 9.8  CPR training
- 9.9  Seizure management training
- 9.10  Emergency management training (fire, flood, etc.)
- 9.11  Behavior modification, behavior shaping training
- 9.12  Physical procedures for managing behavioral crises (PART, CPI, MAB, etc.)
- 9.13  Non-aversive or "gentle" behavior change techniques
- 9.14  AIDS awareness
- 9.15  Normalization
- 9.16  Integration - outings, interactions with neighbors
- 9.17  Individual (client) rights regulations (W & I code)
- 9.18  Special incident reporting requirements
- 9.19  Sexuality
- 9.20  Job development training
- 9.21  Vocational task analysis
- 9.22  Carrying out medical orders
- 9.24  Physical management (positioning, transfers, range, etc.)
- 9.25  Eating assistance, feeding techniques, including alignment
- 9.26  Health care - recognizing and preventing disease
- 9.27  Hygiene - proper procedures for cleanliness and safety
- 9.28  Human rights - individual human rights under law and ethics
- 9.29  Self determination, offering choices, teaching choice-making
- 9.30  Leisure and recreation
- 9.31  Other training: \_\_\_\_\_

10. Do you think you have received sufficient training to do your job?  
1 Definitely Not  
2 Probably Not  
\_\_\_\_\_ 3 Maybe  
4 Yes, Probably  
5 Yes, Definitely

11. Do you think you get sufficient support to do your job?  
1 Definitely Not  
2 Probably Not  
\_\_\_\_\_ 3 Maybe  
4 Yes, Probably  
5 Yes, Definitely

12. How many years of formal education have you had?  
\_\_\_\_\_ years

13. **OPTIONAL:** Approximately what is your pay rate?  
(This information will be kept completely confidential.)

\_\_\_\_\_ Dollars per Year

OR \_\_\_\_\_ Dollars per Hour

(If necessary, accept per week, per month, or per year, and make notes in the margin here; the computer will do the calculations.)

INFORMATION ABOUT THE HOME

Individualized Practices Scale

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INSTRUCTIONS

- (1) Please complete each item by interviewing the respondent (staff person or other caregiver).
- (2) Ask questions in this form: For item #1, "How is waking up handled on weekends and holidays?" Probe the response if necessary, and complete the item according to the answers.
- (3) Omit this scale in an individual home, a foster home, or a family home.

**Weekend/Holiday Schedule**

1. Waking time
  - 0 Fixed - same for all
  - \_\_\_ 1 Fixed - with exceptions
  - 2 Flexible - people get up at different times
2. Bed time
  - 0 Fixed - same for all
  - \_\_\_ 1 Fixed - with exceptions
  - 2 Flexible - people go to bed at different times
3. Dinner time
  - 0 Fixed - same for all
  - \_\_\_ 1 Fixed - with exceptions
  - 2 Flexible - people can eat at different times
4. TV, Radio, and Music times
  - 0 Fixed - times are set for all people by rules
  - \_\_\_ 1 Fixed - with exceptions
  - 2 Flexible - people watch/listen as individuals

**Weekday/Workday Schedule**

5. Waking time
  - 0 Fixed - same for all
  - \_\_\_ 1 Fixed - with exceptions
  - 2 Flexible - people get up at different times
6. Bed time
  - 0 Fixed - same for all
  - \_\_\_ 1 Fixed - with exceptions
  - 2 Flexible - people go to bed at different times
7. Dinner time
  - 0 Fixed - same for all
  - \_\_\_ 1 Fixed - with exceptions
  - 2 Flexible - people can eat at different times
8. TV, Radio, and Music times
  - 0 Fixed - times are set for all people by rules
  - \_\_\_ 1 Fixed - with exceptions
  - 2 Flexible - people watch/listen as individuals

## General Activities

9. Going to work or day program  
0 All people go to the same jobs/day programs  
— 1 Some people go to the same jobs/day programs  
2 Most people go to different jobs/day programs  
9 N/A
10. Recreational trips (malls, parks, sports, walks, etc.)  
0 Always in groups  
— 1 Sometimes in groups, sometimes as individuals or pairs  
2 Usually as individuals or pairs (1 or 2 people with or w/out staff)  
9 N/A
11. Shopping for food  
0 Always in groups  
— 1 Sometimes in groups, sometimes as individuals or pairs  
2 Usually as individuals or pairs (1 or 2 people with or w/out staff)  
9 N/A
12. Doctor, dental, psychiatric, or other health care appointments  
0 Always in groups  
— 1 Sometimes in groups, sometimes as individuals or pairs  
2 Usually as individuals or pairs (1 or 2 people with or w/out staff)  
9 N/A
13. Restaurants  
0 Always in groups  
— 1 Sometimes in groups, sometimes as individuals or pairs  
2 Usually as individuals or pairs (1 or 2 people with or w/out staff)  
9 N/A
14. Worship  
0 Always in groups  
— 1 Sometimes in groups, sometimes as individuals or pairs  
2 Usually as individuals or pairs (1 or 2 people with or w/out staff)  
9 N/A
15. Birthdays  
0 Always in groups, e.g., all June birthdays in one party  
— 1 Sometimes in groups, sometimes as individuals  
2 Celebrated with individual ceremonies, parties, and/or gifts  
9 N/A

Quality of Life Changes

(To Be Answered by the Person or Whoever Knows the Person Best)

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Ask the person to rate the qualities of his/her own life A YEAR AGO and NOW.

If the person can't answer, accept answers from whoever knows the person best.

		1 = Very Bad 2 = Bad 3 = OK 4 = Good 5 = Very Good	Who Answered?  1=Person 2=Surrogate
	A YEAR AGO	NOW	
1. Health	1T. _____	1N. _____	1W. _____
2. Running my own life, making choices	2T. _____	2N. _____	2W. _____
3. Family relationships	3T. _____	3N. _____	3W. _____
4. Seeing friends, socializing	4T. _____	4N. _____	4W. _____
5. Getting out and getting around	5T. _____	5N. _____	5W. _____
6. What I do all day	6T. _____	6N. _____	6W. _____
7. Food	7T. _____	7N. _____	7W. _____
8. Happiness	8T. _____	8N. _____	8W. _____
9. Comfort	9T. _____	9N. _____	9W. _____
10. Safety	10T. _____	10N. _____	10W. _____
11. Treatment by staff/attendants	11T. _____	11N. _____	11W. _____
12. Dental care	12T. _____	12N. _____	12W. _____
13. Privacy	13T. _____	13N. _____	13W. _____
14. Overall Quality of Life	14T. _____	14N. _____	14W. _____

Personal Interview

(To Be Answered Only by the Person)

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INSTRUCTIONS

- o These questions should be answered by the person (with the help of the person's helpers or interpreters, if needed or wanted).
  - o If appropriate and feasible, the interview should be conducted in private.
  - o It may make sense to have a friend, relative, or staff person present to assist please use your judgment.
  - o Try to interview the person, even if there is doubt about ability to respond; B
  - o Never attempt an interview if you have doubts about your safety.
  - o Keep it informal. Begin with the usual social niceties that you would expect f to your home. How are you, telling about yourself, comments on the home, etc.
  - o If the person clearly is not responding or understanding after a little while, note at the end of this section, thank the person, and terminate the interview.
  - o Any item with 5-point scale answers should be thought of as a "YES-NO" or "GOOD 2-point scale, with a chance to get more detail if the person is able. Example: you feel about living here?" and the person answers "Good" then you probe "Would Good or Very Good?" If the person answers "I don't know," or "Not sure," or some indefinite answer, probe with "Do you feel on the good or bad side?" If no prefe with "Fair," which we will interpret to mean "In Between."
1. How do you feel about living here?
- 1 Very Poor
  - 2 Poor
  - \_\_\_\_\_ 3 Fair (In Between, Not Sure)
  - 4 Good
  - 5 Very Good
  - 9 No Answer or Not Applicable - person has no home at present
- 1A. What do you like about living here?  
(Probe: like the best, like the most.)
- 1B. What do you not like about living here?  
(Probe: like the least, dislike.)
2. Who picked this place for you to live in? (REPHRASE AS NECESSARY, USING THE WORDS "CHOOSE," "CHOICES," ETC.)
- 1 Others made the choice (family, professionals, court, etc.)
  - 2 Person had little input
  - \_\_\_\_\_ 3 Person had some input
  - 4 Person had a major say; decision was shared
  - 5 Person chose (even if assisted, person made the final choice)
  - 9 Don't Know or Not Applicable

3. How is the food here? (Rephrase if person cooks for him/herself.)
- 1 Very Poor
  - 2 Poor
  - \_\_\_\_\_ 3 Fair (In Between, Not Sure)
  - 4 Good
  - 5 Very Good
  - 9 No Answer or Not Applicable (e.g., nutrition via tube)
4. Do you get to pick what's made for breakfast, lunch, and dinner?
- 1 Others make the choice (family, professionals, court, etc.)
  - 2 Person has little input
  - \_\_\_\_\_ 3 Person has some input
  - 4 Person has a major say; decisions are shared
  - 5 Person chooses (even if assisted, person makes final choices)
  - 9 Don't Know or Not Applicable
5. How do you feel about the people you live with?  
(NOTE: THIS QUESTION IS ABOUT ROOMMATES WHO HAVE DISABILITIES. IT IS NOT ABOUT STAFF, WIVES, CHILDREN, PARENTS, ETC.)
- 1 Very Poor
  - 2 Poor
  - \_\_\_\_\_ 3 Fair (In Between, Not Sure)
  - 4 Good
  - 5 Very Good
  - 9 No Answer or Not Applicable
6. Did you pick who to live with?
- 1 Others made the choice (family, professionals, court, etc.)
  - 2 Person had little input
  - \_\_\_\_\_ 3 Person had some input
  - 4 Person had a major say; decision was shared
  - 5 Person chose (even if assisted, person made the final choice)
  - 9 Don't Know or Not Applicable
7. Do you have enough privacy?
- 1 Definitely Not
  - 2 Probably Not
  - \_\_\_\_\_ 3 Maybe (In Between, Not Sure)
  - 4 Yes, Probably
  - 5 Yes, Definitely
  - 9 No Answer or Not Applicable (e.g., lives alone)
8. Would like to leave this place and go live somewhere else?
- 1 Definitely Not
  - 2 Probably Not
  - \_\_\_\_\_ 3 Maybe (In Between, Not Sure)
  - 4 Yes, Probably
  - 5 Yes, Definitely
  - 9 No Answer or Not Applicable (e.g., lives alone)
- IF YES, WHERE? \_\_\_\_\_
9. How do you feel about the people who work with you here (the staff)?
- 1 Very Poor
  - 2 Poor
  - \_\_\_\_\_ 3 Fair (In Between, Not Sure)
  - 4 Good
  - 5 Very Good
  - 9 No Answer or Not Applicable; no "staff" who work at the home
10. Did you pick the people who work with you here (the staff)?
- 1 Others made the choice (family, professionals, court, etc.)
  - 2 Person had little input
  - \_\_\_\_\_ 3 Person had some input
  - 4 Person had a major say; decision was shared
  - 5 Person chose (even if assisted, person made the final choice)
  - 9 Don't Know or Not Applicable



11. How do you feel about your [job, day program, workshop, etc.]?  
 1 Very Poor  
 2 Poor  
 \_\_\_\_\_ 3 Fair (In Between, Not Sure)  
 4 Good  
 5 Very Good  
 9 No Answer or Not Applicable
12. Did you pick your [job, day program, workshop, etc.]?  
 1 Others made the choice (family, professionals, court, etc.)  
 2 Person had little input  
 \_\_\_\_\_ 3 Person had some input  
 4 Person had a major say; decision was shared  
 5 Person chose (even if assisted, person made the final choice)  
 9 Don't Know or Not Applicable
13. Do you have friends?  
 1 No Friends  
 2 Just One  
 \_\_\_\_\_ 3 A Few  
 4 Yes, Some  
 5 Yes, A Lot
14. Who is your best friend?  
 1 Staff Member  
 2 Paid Professional  
 3 Advocate, Guardian  
 \_\_\_\_\_ 4 Foster Family Member  
 5 Family Member  
 6 Peer With A Disability  
 7 Unpaid Person Without Disability (Neighbor, Co-Worker, etc.)  
 9 Don't Know or Not Applicable - No Best Friend
15. Do you get lonely?  
 1 Yes, Often  
 2 Yes, Sometimes  
 \_\_\_\_\_ 3 In Between, Not Sure  
 4 No or Very Rarely  
 5 No, Never  
 9 No Answer or Not Applicable
16. Has anyone hurt you recently (the past year)?  
 1 No  
 \_\_\_\_\_ 2 Not sure  
 3 Yes

NOTES:

17. Has anyone made you do something sexual that you did not want to do (recently, in the past year)?  
 1 No  
 \_\_\_\_\_ 2 Not sure  
 3 Yes

NOTES:

18. When you go out places (field trips, shopping, movies, parks, walks, or any other outings), who picks where you go?  
 1 Others make the choice (family, professionals, court, etc.)  
 2 Person has little input  
 \_\_\_\_\_ 3 Person has some input  
 4 Person has a major say; decisions are shared  
 5 Person chooses (even if assisted, person makes final choices)  
 9 Don't Know or Not Applicable

19. Do you like going out to those places?  
1 Not At All  
2 Not Much  
\_\_\_\_\_ 3 In Between, Not Sure  
4 Yes, Some  
5 Yes, Very Much  
9 Don't Know or Not Applicable
20. Would you like to go out more often, or less often?  
1 More Often  
\_\_\_\_\_ 2 About The Same  
3 Less Often
21. Do you have someone who visits you called Case Manager or Support Coordinator (Social Worker at State Hospitals)?  
1 No  
\_\_\_\_\_ 2 Not sure  
3 Yes
22. Can you call (reach) this Case Manager or Support Coordinator (or Social Worker) if you need to?  
1 No  
\_\_\_\_\_ 2 Not sure  
3 Yes
23. Does the Case Manager or Support Coordinator (or Social Worker) help you?  
1 Not At All Helpful  
2 Not Very Helpful  
\_\_\_\_\_ 3 Somewhat Helpful  
4 Very Helpful  
5 Extremely Helpful  
9 Don't Know or Not Applicable - No Case Manager
24. If you had one wish, what would you wish for?
25. Is there anything else you'd like to tell me about what you'd like?

Observation of Person

1. Did you personally visit and see this person?  
0 No [SKIP THIS SECTION - GO TO HEALTH INFORMATION]  
\_\_\_\_\_ 1 Yes
  
2. Is the person dressed appropriately for time and situation?  
0 No  
\_\_\_\_\_ 1 Questionable for situation or environment  
2 Yes
  
3. Are the person's nails clean and trimmed? (Only inspect what you can easily see - do not ask for removal of gloves, footwear, etc.)  
0 No  
\_\_\_\_\_ 1 Yes  
9 Could not observe or not applicable (e.g., lack of extremities)
  
4. Does the person's hair appear to be clean?  
0 No  
\_\_\_\_\_ 1 Yes  
9 Could not observe or not applicable (e.g., no hair)
  
5. Is the person's hair combed and cut or styled appropriately?  
0 No  
\_\_\_\_\_ 1 Yes  
9 Could not observe or not applicable (e.g., no hair)
  
6. Is there any readily visible evidence of cuts, bruises, rashes, sores, or other signs of injury or ill health?  
0 No, no signs of injury or ill health  
\_\_\_\_\_ 1 Yes, there are signs of possible injury or ill health  
DESCRIBE:

Health Information

1. GENERAL HEALTH: In general, how is this person's health?
  - 1 Very Poor
  - 2 Poor
  - \_\_\_\_\_ 3 Fair
  - 4 Good
  - 5 Excellent
  
2. ILLNESS IN PAST 30 DAYS:  
  
\_\_\_\_\_ Number of days of restricted activity because of illness
  
3. DOCTOR VISITS: About how many times has the person been seen by a doctor in the past year?  
  
\_\_\_\_\_
  - 3A. \_\_\_\_\_ About how many visits were for acute illness?
  - 3B. \_\_\_\_\_ About how many visits were for normal preventive care?
  - 3C. \_\_\_\_\_ About how many visits were to specialists?  
What were the kinds of specialists most often seen?
    - 3C-1. \_\_\_\_\_
    - 3C-2. \_\_\_\_\_
    - 3C-3. \_\_\_\_\_
  
4. DENTIST VISITS: About how many times has the person been to the dentist in the past year?  
  
\_\_\_\_\_
  - 4A. \_\_\_\_\_ Number of times for exams, cleaning, and general preventive work
  - 4B. \_\_\_\_\_ Number of times for major work, surgery, or emergency situations
  
5. EMERGENCY ROOM VISITS: About how many times in the past year has the person gone to a hospital emergency room?  
  
\_\_\_\_\_
  
6. HOSPITAL ADMISSIONS: How many times in the past year has the person been admitted to a hospital for any reason?  
  
\_\_\_\_\_
  
7. "MEDICAL HOME": Does this person have a clearly identified primary physician who is responsible for primary care and coordination?
  - 0 No
  - \_\_\_\_\_ 1 Yes
  
8. Who pays for primary medical care for this person?
  - 1 Institution (TSH or Winfield)
  - 2 Medicaid and/or Medicare
  - \_\_\_\_\_ 3 Private Insurance
  - 4 Private Pay
  - 5 Other

9. **PRESCRIBED MEDICATIONS:** Please PRINT the name of each PRESCRIBED medication that the person is receiving. Code the ones that appear on the list on the following page. If there is no code for the medication on the list, leave the code space for that medication blank. (The list of codes includes only psychotropic, or psychoactive, medications.) For each medication, please enter the dosage in whatever units the prescription indicates, the number of times per day, and the purpose. (Some medication regimens are complex, with different doses at different times of day -- try to average these, or add them up to total milligrams per day.) Under PURPOSE, use these codes:

- 1 = Psychiatric Symptoms/Behavior Control
- 2 = Seizure Control
- 3 = Digestive, Stomach, Bowel
- 4 = Chronic Medical Condition  
(Heart, Hypertension, Diabetes, etc.)
- 5 = Other

	NAME	CODE	DOSAGE	TIMES/DAY	PURPOSE
9.1	_____	_____	_____	_____	_____
9.2	_____	_____	_____	_____	_____
9.3	_____	_____	_____	_____	_____
9.4	_____	_____	_____	_____	_____
9.5	_____	_____	_____	_____	_____
9.6	_____	_____	_____	_____	_____
9.7	_____	_____	_____	_____	_____
9.8	_____	_____	_____	_____	_____
9.9	_____	_____	_____	_____	_____

10. **NON-PRESCRIBED (OVER THE COUNTER) MEDICATIONS:** These may include aspirin or other such headache and pain medications, ointments, drops, laxatives, vitamins, and so on.

	NAME	CODE	DOSAGE	TIMES/DAY	PURPOSE
10.1	_____	_____	_____	_____	_____
10.2	_____	_____	_____	_____	_____
10.3	_____	_____	_____	_____	_____
10.4	_____	_____	_____	_____	_____
10.5	_____	_____	_____	_____	_____
10.6	_____	_____	_____	_____	_____
10.7	_____	_____	_____	_____	_____
10.8	_____	_____	_____	_____	_____
10.9	_____	_____	_____	_____	_____

11. NUTRITIONAL STATUS: Does this individual have any special dietary needs?  
0 No  
\_\_\_\_\_ 1 Yes

IF YES, COMPLETE THE FOLLOWING:

11A. Is the person fed by tube?  
0 No  
\_\_\_\_\_ 1 Yes

11B. Is he or she on caloric restriction?  
0 No  
\_\_\_\_\_ 1 Yes

11C. Is the person's food modified in consistency (soft, puree, etc.)?  
0 No  
\_\_\_\_\_ 1 Yes

11D. Does the person receive dietary supplements?  
0 No  
\_\_\_\_\_ 1 Yes

11E. Are there other special dietary needs? IF YES, SPECIFY.  
0 No  
\_\_\_\_\_ 1 Yes

12. Have there been any changes in dietary status within the past year?  
0 No  
\_\_\_\_\_ 1 Yes

12A. IF YES, DESCRIBE WHAT KIND OF CHANGES

13. WEIGHT GAIN OR LOSS: Has this person gained or lost weight within the past year?  
1 Significant Gain  
2 Slight Gain  
\_\_\_\_\_ 3 No Change  
4 Slight Loss  
5 Significant Loss

13A. IF SIGNIFICANT GAIN OR LOSS: Has this weight change been evaluated?  
0 No  
\_\_\_\_\_ 1 Yes

13B. Who evaluated the weight change?  
1 Primary Physician  
2 Nurse  
\_\_\_\_\_ 3 Dietician  
4 Other (specify: \_\_\_\_\_)

14. CURRENT WEIGHT STATUS:  
1 Seriously Underweight  
2 Significantly Underweight  
\_\_\_\_\_ 3 At or Near Weight Ideal for Height and Build  
4 Significantly Overweight  
5 Seriously Overweight

15. SKIN CONDITION (Base these items on interviews with health care staff or other knowledgeable personnel.)
- 15A. Clean?  
0 No  
\_\_\_\_\_ 1 Yes
- 15B. Hydrated (soft, pliable)?  
0 No  
\_\_\_\_\_ 1 Yes, skin is fine
- 15C. Lesions?  
0 No, lesions are not present  
\_\_\_\_\_ 1 Yes, lesions (scratches, breaks in skin, wounds) are present
- 15D. Bruises?  
0 No, bruises are not present  
\_\_\_\_\_ 1 Yes, bruises are present
- 15E. Pressure Sores? (Any red, blistered or open areas on any bony prominences)  
0 No, pressure sores are not present  
\_\_\_\_\_ 1 Yes, pressure sores are present
16. SEIZURE FREQUENCY IN THE PAST YEAR (OF ANY KIND)  
0 Continuous intermittent seizures  
1 More than 5 per day  
2 More than 1 but less than 5 per day  
3 About 1 per day  
\_\_\_\_\_ 4 About 1 per week  
5 About 1 per month  
6 7 to 11 per year  
7 1 to 6 per year  
8 Has documented history of seizures, but none in past year  
9 No seizures
17. INJURIES: Has this person had any injuries in the past year?  
0 No  
\_\_\_\_\_ 1 Yes
18. HOW MANY? (Enter a ZERO if none.)  
\_\_\_\_\_
19. HAVE ANY INCIDENTS OR ALLEGATIONS OF ABUSE OCCURRED?  
0 No  
\_\_\_\_\_ 1 Yes
20. HOW MANY? (Enter a ZERO if none.)  
\_\_\_\_\_
21. How easy is it to find medical care for this person?  
1 Very Difficult  
2 Difficult  
\_\_\_\_\_ 3 About Average  
4 Easy  
5 Very Easy
22. RESPONDENT OPINION: Overall, how good is this person's health care?  
1 Very Poor  
2 Poor  
\_\_\_\_\_ 3 Fair  
4 Good  
5 Excellent

Home Physical Quality Scale

From Moos, Lemke, & Mehren, 1979, MEAP;

Modified by Temple University, 1983

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INSTRUCTIONS:

- (1) This section is to be completed in private, after a tour of the home.
- (2) Avoid giving the impression of "taking notes" during the tour.
- (3) Some of the judgements may seem subjective, but please try to give ratings according to the concept of an "American average" home.

SECTION 1: EXTERNAL

1. As a neighborhood, how does the area around this home look?
  - 3 Very pleasant and attractive
  - 2 Mildly pleasant and attractive
  - \_\_\_\_\_ 1 Ordinary, perhaps even slightly unattractive
  - 0 Unattractive, slum-like
2. How attractive are the home's grounds?
  - 3 Very attractive - as nice as, or nicer than, the grounds of the surrounding homes
  - 2 Somewhat attractive
  - \_\_\_\_\_ 1 Ordinary
  - 0 Unattractive - the grounds stand out as being "different" and less attractive
3. How attractive is the building?
  - 3 Very attractive - attractive design, excellent maintenance
  - 2 Somewhat attractive
  - \_\_\_\_\_ 1 Ordinary
  - 0 Unattractive - building is deteriorated or unattractive

SECTION 2: ROOM BY ROOM

4. Orderliness
  - 3 Neat - living spaces are very orderly
  - 2 Some disarray
  - 1 Cluttered
  - 0 Very cluttered - furniture and other objects are in disarray
  - 9 No such room at this residence

LIVING ROOM    DINING ROOM    BEDROOMS    KITCHEN    BATHROOM

5. Cleanliness
  - 3 Very clean
  - 2 Clean
  - 1 Dirty
  - 0 Very dirty
  - 9 No such room at this residence

LIVING ROOM    DINING ROOM    BEDROOMS    KITCHEN    BATHROOM



6. **Condition of furniture**  
 3 Excellent condition - like new, well-kept  
 2 Good condition  
 1 Fair condition  
 0 Deteriorated - old and in poor repair  
 9 No such room at this residence

LIVING ROOM    DINING ROOM    BEDROOMS    KITCHEN    BATHROOM

7. **Window areas**  
 3 Many windows  
 2 Adequate windows  
 1 Few windows  
 0 No windows  
 9 No such room at this residence

LIVING ROOM    DINING ROOM    BEDROOMS    KITCHEN    BATHROOM

8. **Odors**  
 3 Fresh - air is fresh and pleasant  
 2 Neutral or unexceptional  
 1 Slightly objectionable  
 0 Distinctly objectionable - unpleasant odors are apparent  
 9 No such room at this residence

LIVING ROOM    DINING ROOM    BEDROOMS    KITCHEN    BATHROOM

**SECTION 3: OVERALL**

9. **Variation in decor of peoples' rooms (apartments.)**  
 3 Distinct variation - decor varies from room to room  
 2 Moderate variation  
 1 Little variation  
 0 Identical - little or no variation
10. **Personalization of peoples' rooms (apartments.)**  
 3 Much personalization - most of the furnishings and objects in the rooms belong to the individual  
 2 Some personalization  
 1 Little personalization  
 0 No personalization is evident
11. **Overall physical pleasantness of the home**  
 3 Quite pleasant  
 2 Pleasant  
 1 Somewhat unpleasant  
 0 Distinctly unpleasant
12. **Neighborhood safety impressions**  
 3 Very safe neighborhood  
 2 Reasonably safe neighborhood  
 1 Somewhat unsafe neighborhood  
 0 Distinctly unsafe neighborhood

## ELEMENTS OF NORMALIZATION

Adapted from Wolfensberger & Glenn, 1975

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Rate these items after the visit is finished, using your general impressions. The i may be somewhat subjective, and that is OK.

### 1. STAFF ATTITUDES TOWARD PEOPLE LIVING IN THE HOME

- 5 IDEAL: Warmth, affection, and optimism for the future concerning the people living in the home
- 4 GOOD: Positive feelings toward the people
- \_\_\_\_\_ 3 FAIR: Neutral feelings toward the people, sometimes called "professional attitude," but characterized by overall lack of positive emotional expression
- 2 POOR: Negative feelings toward one or more of the people, such as disdain, contempt, hostility
- 1 UNACCEPTABLE: Negative feelings toward all or most of the people

### 2. OVERALL INTEGRATION OF HOME

- 5 IDEAL: House or apartment in a regular neighborhood, and is not "next to or very near" other homes or programs for people with special needs, and the neighborhood has a good "image" (in a wealthy suburb, near a respected college, etc.)
- 4 GOOD: Regular neighborhood, and not "next to or very near" to other special homes or programs
- \_\_\_\_\_ 3 FAIR: Regular neighborhood, but is "next to or very near" to other special homes or programs
- 2 POOR: In a neighborhood that is not "regular;" mixed commercial and residential, or in the midst of many or large special homes or programs
- 1 UNACCEPTABLE: Glaringly segregated situation, such as a large institutional setting, or an area with practically nothing but special homes and programs

### 3. PERSON-CENTERED ORIENTATION:

- 5 IDEAL: Each individual is thought of, described as, and treated as, a unique person with unique wants and needs, and this is abundantly clear during the entire visit
- 4 GOOD: Same as 5, but less strongly so
- \_\_\_\_\_ 3 FAIR: Midway between IDEAL and UNACCEPTABLE
- 2 POOR: People are often "lumped together" as a group who are all treated similarly
- 1 UNACCEPTABLE: The people here are clearly not being thought of, described as, or treated as, unique individuals.

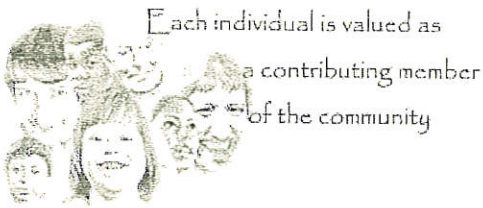
## **Appendix B**

### **Open-Ended Comments of Staff:**

**“If you could have one wish granted for this person,  
what would you wish for?”**

## Comments Arranged In Alphabetical Order

ALL THE DRINKS SHE WANTED	NOT HAVE CANCER
BE ABLE TO SEE	PERFECT HEALTH
BE CALM+HAPPY+WALK	POOP ON HER OWN
BE MORE ALERT	REACH HIS POTENTIAL
BE MORE MOBILE	REACH HIS POTENTIAL
BE NORMAL	RIDE HORSES
BE NORMAL	SEE A MAJOR SPORT EVENT
BEING HEALTHIER	SEE FAMILY MORE OFTEN
BEING NORMAL	SEE FAMILY MORE
COMMUNICATE THOUGHTS BETTER	TELL WHAT HE WANTS
COMPLETE MOBILITY	TELL WHAT IS WRONG
DO MORE FOR HIMSELF	THAT HE COULD TALK
EAT REAL FOOD	TO BE A SINGER
FIGURE OUT WHAT PROBLEMS ARE	TO BE NORMAL
GET ALL HIS DREAMS	TO BE NORMAL
GET HIS HIPS TAKEN CARE OF	TO BE NORMAL
GET WHATEVER HE WANTS	TO BE NORMAL
GO TO A SPA HAVE DAY OF OWN	TO BE NORMAL
GO TO NASCAR RACE	TO BE NORMAL
GOOD HEALTH	TO BE NORMAL
GOOD HEALTH	TO BE NORMAL
GOOD HEALTH	TO BE NORMALIZED
GOTO LION KING ON BROADWAY	TO GO TO HEAVEN
HAVE ALL GOOD HAPPY DAYS	TO HAVE A JOB
HAVE OWN CAR+TO DRIVE	TO HAVE CHOICES
HEALTH STATUS TO IMPROVE	TO HAVE SIGHT
HIS HEALTH IMPROVE	TO LEARN INDEPENDENTLY
LIVE W/HIS PARENTS	TO LIVE ON HIS OWN
LIVE LIFE TO THE FULLEST	TO SEE
MAINTAIN INDEPENDENCE	TO SEE
MORE 1-1 ATTENTION	TO SPEAK AGAIN
MORE 1-1 ATTENTION	TO SPEAK+TELL US WHAT SHE WANTS
MORE 1-1 OUTINGS	TO TALK
MORE 1ON1 ATTENTION	TO TALK
MORE FLEXIBLE,MUSCLE TONE	TO TALK
MORE INDEP IN MOBILITY	TO TALK
MORE PHYSICALLY ABLE	TO WALK
MORE PHYSICALLY ABLE	TO WALK
MORE PHYSICALLY ABLE	TO WALK BETTER
MORE PHYSICALLY ABLE	UNDERSTAND HER BETTER
MORE SELF IMPROVEMENT	UNDERSTAND THINGS MORE
MOVE FREELY INTO BACKYARD	VERBALLY COMMUNICATE
NOT BE IN WHEELCHAIR	WISH HE HAD HIS SIGHT
NOT BE MENTALLY RETARDED	WISH HE COULD TALK



## *Shattering Myths* about Quality of Life & Quality of Services

***Q: Has moving from institutions to small community homes been successful? Are outcomes for people better in the community?***

**A: Yes.**

- Research demonstrates that moving people from institutions to the community has been extremely successful and that outcomes for people in the community are better than for individuals segregated in institutions.<sup>i</sup> Recent research has also found this to be true of people with very serious challenges.<sup>ii</sup> In fact, from the large body of research evidence now available, researchers make this statement:  
*“Deinstitutionalization of people with developmental disabilities in America has been one of the most successful and cost-effective social experiments in the past two decades.”<sup>iii</sup>*

***Q: Do parents who fear their loved ones will not be safe and will suffer in the community continue to feel this way after their family member leaves the institution?***

**A: No.**

- Research shows that family member attitudes change dramatically after community placement. Before community placement, less than 20% of families agreed with community placement and 58% strongly opposed community placement; However, after placement, 66% of families strongly agreed with community placement and less than 5% opposed.<sup>iv</sup>

***Q: Is community living a “one size fits all” approach?***

**A: No.**

- Smaller community settings are more likely to address unique needs and preferences than larger institutions. Community programs, including staff training, are designed around the needs of the person.
- Everyone who leaves a DDA institution does so ONLY after thorough individualized team planning and when all needed community-based services and supports have been identified. In addition, everyone leaving an institution is assigned a resource coordinator to monitor and assist in carrying out his or her plan.
- It is actually institutions – with large numbers of people and set routines – that epitomize “one size fits all.”

***Q: Is there widespread abuse in community programs? Are institutions safer?***

**A: No.**

- Institutions and community programs in Maryland are licensed and certified by the same state and federal agencies. When people live in the community, neighbors, friends, and the public can see and report any abuse--something less likely to happen for an individual living in an isolated setting.
- A recent study found allegations of abuse actually decreased after community placement.<sup>v</sup>
- Direct comparisons of the number of abuse allegations in institutions and community programs are misleading, as they must be considered in the context of the total number of people served -- 22,000 people with developmental disabilities are supported in community programs while about 400 people live in institutions.
- Abuse, unfortunately, also occurs in institutions.

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**Q** en't institutions home-like?

**A:** No.

- “As much as we try to create a home-like environment in an institution, institutions are not homes. You cannot take 200 people and create a home. It’s not individual. And you just cannot measure the importance of environment.” ~ Bill Brooks, retired superintendent of Winfield State Hospital<sup>vi</sup>

**It is NOT reasonable to segregate people in institutions when experience and research prove that even people with significant disabilities and intensive needs can be supported in the community.**

**It is NOT reasonable to continue to invest scarce public dollars operating large, inefficient congregate settings.**

**It is NOT reasonable to deny even one person the right to live among us in the community, where services and supports can be provided.**

<sup>i</sup> Lakin, K.C. (1999). *A review of literature of home and community services for persons with mental retardation and related conditions*. Minneapolis: University of Minnesota, Research and Training center on Community Living, Institute on Community Integration.

<sup>ii</sup> Conroy, J., Spreat, S., Yuskasuskas & Elks, M. (2003). The Hissom Closure Outcomes Study: A Report on Six Years of Movement to Supported Living. *Mental Retardation*. 41, 263-273.

<sup>iii</sup> Conroy, J., Garrow G., Fullerton, A., Brown, M. & Vascile, F. (2003). *Initial Outcomes of Community Placement for the People Who Moved From Stockley Center*. Completed for the Delaware Division of Developmental Disabilities Services.

<sup>iv</sup> Conroy J. & Bradley, V. (1985). *The Pennhurst Longitudinal Study: A Report of Years of Research and Analysis*.

<sup>v</sup> Conroy J., et. al (2003). *Initial Outcomes of Community Placement for the People Who Moved From Stockley Center*.

<sup>vi</sup> *The Right Thing To Do*. 1998. The Kansas Council on Developmental Disabilities.

**MARYLAND DEVELOPMENTAL DISABILITIES COALITION**

People on the Go of Maryland • The Arc of Maryland • Maryland Association of Community Services  
Maryland Developmental Disabilities Council • Maryland Disability Law Center

Let's Focus on the Real Issues

Steven M. Eidelman, Renee Pietrangelo, James F. Gardner, George Jesien,  
and M. Doreen Croser

This article was written in response to a 4-page paper entitled "Executive Summary: Institutional and Community-Based Systems for People With Mental Retardation: A Review of the Cost Comparison Literature," which was funded and widely disseminated by the Voice of the Retarded-VOR (2002). In this Executive Summary, which is described by VOR as a "research tool," an analysis of existing studies of costs of supports and services for people with mental retardation and developmental disabilities is reported. It is noted in the summary that it is a "slightly modified" version of a manuscript submitted for publication. Although we have not reviewed the manuscript submitted for publication and cannot comment on it, the Executive Summary is an example of how research can be turned into a call for poor public policy.

Developmental Disabilities Quality Coalition (DDQC) is comprised of the chief staff executives of The Arc of the United States, American Association on Mental Retardation, American Network of Community Options and Resources, Council on Quality and Leadership, National Association of State Directors of Developmental Disabilities Services, American Association of University Centers on Disabilities, National Association of Protection and Advocacy Systems, National Alliance of Direct Support Professionals, Consortium of Developmental Disabilities Councils, and National Association of Developmental Disabilities Councils. Members of this coalition are gravely concerned about the misguided interpretation of this Executive Summary as it relates to the national agenda for full inclusion, choice, and person-centered outcomes for people with mental retardation and developmental disabilities. In addition to the DDQC and numerous other advocacy and disability organizations nationwide, this agenda is supported at the highest levels of public policy by the current Bush Administration through its "New Freedom Initiative" and by the Supreme Court in its Olmstead decision.

It is imperative that we place this report in its proper historical context. Deinstitutionalization has been taking place in the United States for the past 3 decades. In the 1990s alone there was a 44% decline in the number of persons in state-operated institutions Lakin, Prouty, Polister, & Smith, 2002). It is critical to note that these reductions were not driven primarily by potential cost savings. In so many cases, states also "matched" someone leaving the institution with someone at home waiting for services. These institutions closed and others are continuing to close because it is the right thing to do, not because it will save money. The best estimate is that all institutions will be closed somewhere between 2011 and 2025, the later date adjusted for slower progress in Georgia, Illinois, Kentucky, Louisiana, Mississippi, New Jersey, Oklahoma, Tennessee, Texas, and Virginia (Braddock, Hemp, Rizzolo, Parish, & Pomeranz, 2002).

The disability field has, over these past 3 decades, learned to separate "level of care" from real estate. They are two separate issues. Where the needed supports for a person take place and the frequency, intensity, and duration of those supports are two separate issues.

There has been a national movement to promote "The Community Imperative (1979)", which every member of the DDQC has endorsed. The Community Imperative states, in part:

\* All people have fundamental moral and constitutional rights.

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- \* These rights must not be abrogated merely because a person has a mental or physical disability.
- \* Among these fundamental rights is the right to community living.
- \* All people, as human beings, are inherently valuable.
- \* All people can grow and develop.
- \* All people are entitled to conditions that foster their development.
- \* Such conditions are optimally provided in community settings.

Note that nowhere in The Community Imperative, which is a civil rights and social justice statement, is there any mention of cost. The question of the comparative costs of institutional versus community services is not relevant; it is a non-issue. The real question is: Under what circumstances should or, more important, will the taxpaying public pay for 24-hour wrap-around services for people with disabilities regardless of the setting in which those services are provided? In institutions, the taxpaying public is paying for services that are shown to produce poor outcomes for the people served. Clearly, this is poor public policy.

Discussions of comparative costs have been going on ever since people started mounting serious threats to the existence of institutions. The fundamental question that needs to be addressed is whether or not we, as a society, want to have those among us who have disabilities receive the supports they need in their own local communities, close to families and friends, or do we want to segregate them from the rest of society in congregate settings?

Does it make sense to label and categorize people on the basis of some characteristic and treat them as if the condition they have is the most important thing about them? Is this categorization so important, in fact, that it is a legitimate interest of the state to offer alternatives for the provision of needed care and support that, in fact, force people to trade their human and civil rights for services? Doesn't our nation's Constitution have something to say about this?

If it is agreed that people should not have to actually leave society in order to receive the basic support they need to live their lives, then it does not make sense to offer needed supportive services outside the community setting. Again, this is not an issue of cost; it is an issue of civil rights. Other than the criminal justice system, we cannot think of another situation where such restrictions take place nor one that tolerates the effective control of one group by another. In specific response to the points noted in the Executive Summary, the DDQC offers the following comments:

1. From the studies reviewed here, it is clear that large savings are not possible within the field of developmental disabilities by shifting from institutional to community placements. ("VOR, 2002")

Placements are not the issue. Most people with mental retardation live with their families and have never lived in institutions. Their families provide for them because of love and necessity. The fallacy that those in institutions are somehow different and "more severely challenging or disabled" is not borne out by the research or by common sense. The question is one of fairness and resource allocation; although those in institutions may have numerous services available, many families are supporting their family member who has severe disabilities with little or no public support. There is also the issue of how the funds are spent. Institutions have their own electricians, plumbers, power plant operators, roads, and maintenance personnel. In the community, those things are there for everyone and are part of rent, taxes, or general citizenship. Community programs concentrate on the people, not buildings.



2. The scope of the present literature review did not allow for the simultaneous review of research on the many clinical and quality of life outcomes but noted the importance of including in policymaking consideration [of] a full range of individual outcomes. ("VOR, 2002")

The literature review refutes the argument made by some institutional proponents that economies of scale and centralized services make institutions more economical than community services. The research on outcomes overwhelmingly makes it clear that the outcomes for people in the community are better than those for individuals segregated in institutions (Lakin, 1999). In a well-constructed study, investigators would have looked at both issues simultaneously. Good public policy supports good outcomes and human rights, especially when there is no significant cost advantage to either form of service and support.

3. Clear-cut evidence was not found in the studies reviewed to support the unambiguous conclusion that community services are inherently less expensive than institutional settings. (VOR, 2002)

From the studies reviewed here, it is clear that large savings are not possible within the field of developmental disabilities by shifting from institutional to community placements. Again, the issue of note is that most people with developmental disabilities are not now nor have they ever been in an institution, that institutions are inhumane and violate people's rights, and that there is virtually no demand, except from the small membership of VOR, to keep institutions open or to admit people to them. It is also apparent that approaches such as self-determination and individualized budgeting were not analyzed in the Executive Summary, even though these are the issues of utmost importance. Determining resources that provide what people really want and need, as opposed to a rigid package, should be explored. The Intermediate Care Facility (ICF) program and the myth of something called "active treatment" make assumptions about people's deficits and then designs a program within the confines of the active treatment framework to address them. Active treatment was designed in the early 1970s to deal with the lack of anything positive in the environment in institutions-not as a panacea for a way to help people with developmental disabilities lead lives of meaning.

4. Public policy should not be generalized statements about cost-efficiency, rather, they should revolve around the individual and his/her needs: "What does this person need?" "Where best to provide for these needs?" and "At what cost?" (VOR, 2002)

We agree with this statement. Person-centered approaches, practicing self-determination, and a solid understanding of a person's needs will lead to the best services and supports. When these are present, the setting will not be an institution. Gross comparisons between costs in institutions and the community oversimplify the costs associated with different ways of supporting people in the community. They also ignore the benefits, which study after study have demonstrated is substantially higher in the community.

5. Finally, a factor that has been included only sporadically in the literature or, in some cases, not at all, has to do with the variability in the characteristics of those being served (referred to

here as case mix). Individuals with mental retardation and related developmental disabilities are quite heterogeneous with some individuals being nearly indistinguishable from people without disabilities to those who are quite disabled and dependent. Over the period reviewed, it has been typical for a higher proportion of individuals with mild disabilities to live in community settings while people with more complex needs requiring extensive care remained in institutional facilities. (VOR, 2002)

Most people live in the community and always have. Therefore, to compare the cost of most people in the community to a small subset of those remaining in institutions is inaccurate and misleading. The true comparison would be the cost for all people with similar disabilities in the community, including those who receive minimal or no public support.

The DDQC was compelled by moral obligation and commitment to respond to the obfuscation of the real issues generated by the Executive Summary and the subsequent policy interpretations extrapolated by VOR. We are confident that the arguments set forth herein clarify the relevant issues implicit in today's public policy debate regarding supports and services for people with mental retardation and developmental disabilities.

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#### The Editor's Perspective on Institutional and Community Costs

This issue of the *Journal* contains a research review by Walsh, Green, and Kastner (2003) on cost comparisons of institutional and community services. The response that follows by the Developmental Disabilities Quality Coalition-DDQC (Eidelman, Pietrangelo, Gardner, Jesien, & Croser, 2003), a consortium of nine national groups, refers to an Executive Summary that has been widely distributed by Voice of the Retarded (VOR), a group that provided financial support for the research review. I first became aware of VOR's Executive Summary when I was contacted in July 2002 by several people in Washington, DC, who inquired about whether the Walsh et al. article was forthcoming in the *Journal*. (I confirmed that it was but declined to provide copies.) A copy of this Executive Summary was sent to me, along with "Talking Points and Action Steps" prepared by VOR, in which the summary was described as an advocacy tool to use with policy makers to oppose the "aggressive push towards deinstitutionalization." I subsequently accepted for publication the following response by the DDQC (Eidelman et al., 2003) to VOR's Executive Summary. This response is not, and should not, be interpreted to be a critique of the Walsh et al. article published in this issue. The response is directed at the Executive Summary and the advocacy materials distributed by VOR. The authors of this response could not comment on the Walsh et al. article or criticize their methodology and findings simply because the article was not available to them.

The reason I accepted the DDQC response is that VOR's Executive Summary has been disseminated to policy makers and discussed in policy circles. In the materials by VOR, numerous references were made to the fact that the research review was forthcoming in a peer-reviewed journal and implied that this review countered one of the major arguments in favor of deinstitutionalization and community inclusion. The DDQC response provides a different perspective on the relevance of cost in the institution versus community debate.

In VOR's Executive Summary a footnote was included signifying that "a slightly modified manuscript has been submitted for publication." The manuscript accepted for publication in the *Journal* is not a "slightly modified" version of the Executive Summary. The Executive Summary is missing the essential information—the methodology, the list of studies reviewed, the interpretations of the findings of these specific studies—to enable the research and scholarly community to evaluate the research reviewers' conclusions. No single study or research review is ever definitive or conclusive. Readers of this and other journals know that published articles sometimes generate responses or stimulate additional research and analyses in which other researchers come to conclusions opposite to those in the originally published work. This is why authors of peer-reviewed research articles are expected to provide specific descriptions of their methodology.

The contribution of Walsh et al. (2003) in their research review, in my opinion, is that they draw attention to the complexity of cost comparisons and identify some of the major factors that should be taken into consideration. For example, Walsh et al. pointed out that lower costs in community settings often reflect differentials in staffing costs. Staff members at state-operated

institutions tend to receive higher wages and benefits than do workers at privately operated community settings. Walsh et al. noted, and I agree, that the lack of parity in wages and benefits between workers at institutions and community settings is not a "desired efficiency," but it is not a foregone conclusion that parity will be achieved in the foreseeable future.

When I made the decision to accept Walsh et al.'s research review, I was not influenced by the potential political implications of publishing the article. I never am when making editorial decisions on manuscripts submitted for peer-review.

Any set of findings or facts can lead to different conclusions and policy implications. If Walsh et al.'s (2003) article suggests that community settings are not inherently less expensive than are institutions, then it also refutes claims that institutions offer "economies of scale" or that the centralization of services at institutions is more cost-effective. The "institutional bias" of the federal-state Medicaid program, alluded to by Walsh et al., cannot be justified on fiscal grounds.

I consider the Walsh et al. (2003) research review to be a valuable addition to the literature on cost analysis of developmental disability services and hope that readers will evaluate it according to its contribution to the field by identifying factors that should be considered in cost comparisons. It would be unfortunate if people in the field viewed it as ammunition in a political debate. This is not why I accepted this research review for publication, and it is not what I think that we can learn from it.-S.J.T.

Editor's Note: The American Association on Mental Retardation (AAMR) is a member of the Developmental Disabilities Quality Coalition. Editorial decisions on manuscripts submitted to the Journal are made without regard to the position statements of AAMR. The Board of Directors and personnel from the National Office of AAMR have never attempted to influence the editorial decision-making process of the Journal. Further, when this response was originally accepted, AAMR was not associated with it.

Eidelman, S. M., R. Pietrangelo, J. F. Gardner, G. Jesien, and M. Doreen Croser. (2003). Let's focus on the real issues. *Mental Retardation*, 41.

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Testimony to:  
Senate Ways and means Committee  
Senator Steve Morris, Chair  
March 2, 2004

My name is Gina McDonald and I represent the Kansas Association of Centers for Independent Living (KACIL). KACIL represents the 13 Centers for Independent Living (CIL's) around the state. Our mission is to coordinate efforts within Kansas, the United States, and internationally to the extent that these efforts will further independent living for all. KACIL will advocate for the civil rights of Kansans with disabilities, regardless of age.

KACIL rises in strong support for SB 531.

KACIL believes in the freedom and dignity of every individual. A person who has committed no crime should not be sentenced to an institution. Yet people with developmental disabilities have received life sentences under the guise that it is for their own good. What can you possibly do for an individual behind the walls of an institution that you cannot do for them behind the walls and doors of a home?

In the late 1970's, the Courts recognized the rights of people to live in the least restrictive setting in the Pennhurst decision. Yet in 2003 we are still debating whether to close facilities. In 2003 we in Kansas still fund two institutions for people with developmental disabilities, even though we have successfully closed Norton State Hospital and Winfield State Hospital.

So for KACIL it is not a matter of whether you will close institutions, the questions are when and how? Of course we must close institutions. Not for a cost savings, but because we know for a fact that people with developmental disabilities can and do succeed in community based settings. They do not succeed and flourish in institutions, in fact you have data to prove that they do not. The December 1998 report "Are People Better Off? Outcomes of the Closure of Winfield State Hospital" by James Conroy states that people who left Winfield State Hospital are better off and are learning new skills. They are healthier,

even though they are having less doctor visits, their families visit them more and they are much more actively engaged in their communities.

In my visits to Winfield State Hospital, almost all residents were "confined" to wheelchairs. My friends in the disability rights movement would be upset if they heard me use that term, because most people who use wheelchairs see them as their freedom, not confinement.

But the wheelchairs I saw at Winfield in which over 90% of the residents were placed were chairs with four very small wheels. This made it difficult if not impossible for the resident to move the chair themselves.

I wonder how many people still need to use wheelchairs since they've moved to the community. I have anecdotal reports from community service providers who told me that residents that came from Winfield, after a month or so no longer needed to use wheelchairs. A miracle? I think the only miracle is that we realize that institutions by their nature are designed to keep the place running smoothly, not to enhance individual rights and skills.

The Conroy report also discusses the success of closing institutions for people with MR/DD in other states. We can learn from our own lessons and the successes of other states as Kansas looks to close another institution.

Kansas will have some major challenges to consider as we look at deinstitutionalizing our services. KACIL believes those issues include, but are not limited to:

## 1. THE DD FUNDING SYSTEM.

### ISSUE.

As long as the State continues to use a managed care mentality for providing services to people with developmental disabilities, the system will not work for people with severe disabilities. People leaving facilities will need individualized programs and funding streams in order to achieve success. The program plan will need to allow for flexibility so that changes can be made and paid for without negative consequences either to the provider or the consumer.

The current system is designed to keep people where they are at, not to improve or achieve outcomes. As people gain more skills the community service providers are "rewarded" by getting less funding. With individualized funding or fee for service, the provider is only paid for services provided. The consumer has the opportunity to learn skills in the most appropriate and least restrictive setting to meet their needs.



Bundling of services, along with the "tier" system make it very difficult and cost prohibitive to provide individual services. For example, how can I select my own attendant when the group home employs the attendant and the needs of the whole group must be taken into account?

How can I "de bundle" services by getting a job coach to come with me on a job when they work with ten other people at the sheltered workshop?

#### SOLUTION.

If not for all, at least for people leaving the state institutions have individual rates for services on a plan of care. If the service is not used, you don't pay for it. If it is, it is individualized and you pay for it. This should continue as long as the person receives services.

That doesn't mean someone can't live in a group home or a workshop, but you would pay for their services as they get them. This would also allow the flexibility and creativity to meet individual needs.

A real individual plan would allow for creating solutions to challenging behaviors that some individuals will have as a result of their disability and in some cases as a result of years of institutional behavior.

This can also increase the capacity of the consumer and their family to choose the provider of choice.

#### 2. ENTITLEMENT.

As you are aware, institutions are an entitlement under Title XIX and Home and Community Based Services are an option to the state. As you downsize or eliminate institutions, will HCBS become the entitlement? As we look to recent Supreme Court cases such as *Olmstead* and the *Fisher v. Oklahoma* case we are seeing a trend by the Courts which move us closer to community entitlement. The Medicaid Community Attendant Supports and Services Act (MiCASSA) currently has many cosponsors including all Kansas House Members and Senator Pat Roberts. When that law passes, community services will be an entitlement.

The White House introduced their "New Freedom Initiatives" and many states including Kansas have received grants to plan for consumer controlled community based services.

What will that mean for state budgets? How will long term care programs look and be funded in the future? I don't have solutions that you are ready to



embrace, but I suggest that we begin the dialogue around these issues as we consider closing institutions.

Further dialogue may be beneficial to determine the definition of institutions and as we plan for downsizing. Let's be clear as to what we mean by that term. It's easy to define that as "Parsons State Hospital and KNI". But many of us would contend that IFC/MR's are also institutions, and most of the members of KACIL would also add group homes to that definition.

### 3. THE WAITING LIST AND THOSE PEOPLE WHO CONSIDER THEMSELVES TO BE UNDERSERVED.

#### ISSUE.

How will the people who have been waiting for services be considered as we look at possible hospital closure? KACIL believes very strongly in moving people out of facilities first. But once again we are saying that people who have kept their children at home at little or no cost to the state will go to the back of the line while people who felt they needed to institutionalize their child will get services first.

#### SOLUTION.

As we consider closure and downsizing let's do it for the right reason. Let's make decisions based on the fact that we believe that people can get needed services in more integrated natural living situations. Let us not consider this as a cost savings measure. Yes, we know it costs less to provide services in the community, but as we consider closing institutions and realize savings, let's put those dollars toward the waiting lists and provide services to everyone who qualifies.

### 4. CLOSURE DECISION.

A number of advocates got together and proposed some steps to be taken in closing a facility. KACIL supports those steps as a roadmap for closure.

If you create a Closure Commission we ask for representation by members of Self Advocates Coalition of Kansas and People First to be included as commission members.

In closing, I have worked with people with developmental disabilities in one capacity or another for over 25 years. I have never met one person who said they'd like to go back to the institution, except maybe to visit friends who live there. I never heard positive stories about their time in institutions and some of





the stories I heard were horrific. I've never heard a non disabled person say, "When I grow up, I want to go live in an institution!"

Will there be challenges and people with difficult behaviors? Of course there will. Are the problems so big they cannot be resolved? No, absolutely not. Any program that can be implemented inside the walls of an institution can also be implemented inside the walls of a home.

Are community services ready? Yes, I believe they are, as long as there is adequate funding, supports and flexibility.

Thank you for the opportunity to speak with you today. If you have any questions, I can be reached at 785-825-2675.



Self-Advocate  
Coalition of Kansas

DATE: March 2, 2004

TO: Senate Ways & Means Committee

FROM: Kathy Lobb, Legislative Liaison, SACK

RE: Senate Bill 531

Thank you for the opportunity to speak today.

My name is Kathy Lobb. I am representing the Self-Advocate Coalition of Kansas better known as SACK. SACK is the state advocacy group for adults with developmental disabilities. SACK is a member of the Big Tent Coalition.

I have lived in an institution and I now live and work in the community. I am also now a taxpayer. My life is an example of the benefits of living in the community. I believe that with the right supports all individuals with Developmental Disabilities can live in the community.

SACK supports closure of State Hospitals for people with Developmental Disabilities. Therefore we ask you to support SB 531 that will create a Hospital Closure Commission. It is important to keep the language that ensures representation on the commission by a consumer with a developmental disability, a family member or guardian, and an advocate. These are people who must be included in the discussion of hospital closure.

It is also vitally important that funding follow people into the community of their choosing. A consumer should not have to live in an institution in order to receive the supports they need throughout their life. We remind you that it is less expensive to live in the community than in an institution and gives individuals the opportunity to contribute to society.

Creating this commission is a good first step in working towards community living for all. This bill gives the State the opportunity to begin much needed long range planning for delivery of Developmental Disability services. We hope that you take this opportunity to ensure all Kansans can enjoy the freedom of choice and independence they deserve.

I appreciate this opportunity to speak to you and will stand for questions.



Kathy Lobb, Legislative Liaison  
Self Advocate Coalition of Kansas



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Room 236  
Lawrence, Kansas 66046

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785-749-0121

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Email: kssack123@aol.com

Web: kansassack.org

Senate Ways and Means  
3-8-04  
Attachment 8



## KANSAS ADVOCACY & PROTECTIVE SERVICES, INC.

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Topeka KS 66610

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(877) 776-1541 TDD/Voice

Web site: [www.ksadv.org](http://www.ksadv.org)

e-mail: [info@ksadv.org](mailto:info@ksadv.org)

### Testimony to the Senate Ways and Means March 2, 2004

Chairman Morris and members of the Committee, my name is Rocky Nichols. I am the Executive Director for Kansas Advocacy and Protective Services (KAPS). KAPS is a public interest legal advocacy agency, part of a national network of federally mandated and funded organizations legally empowered to advocate for Kansans with disabilities. As such, KAPS is the officially designated protection and advocacy organization for Kansans with disabilities. KAPS is a private, 501(c)(3) nonprofit corporation, independent of both state government and disability service providers.

One of our core priorities is to “promote positive systems and policy changes that will increase the independence of Kansans with disabilities and enable them to live with dignity, independence and respect in the most integrated setting possible.”

SB 531 lays out a structure under which the remaining state Developmental Disability (DD) Institutions could be closed. KAPS agrees wholeheartedly with the goal behind SB 531 because we strongly support the most integrated, community-based services over institutional based services. As laid out in SB 531, the Developmental Disabilities Institutions Closure Commission will recommend closure of at least one of the two remaining DD hospitals in Kansas, and *may* recommend downsizing or closure of the other. KAPS respectfully suggests a slightly different and enhanced approach. Approximately a dozen states have closed either all their private or public Intermediate Care Facilities for persons with Mental Retardation (ICF/MRs). Therefore, we would ask that you amend SB 351 to have the Closure Commission study and recommend a date when all large-bed ICF/MRs, both private and public, will be closed. Then, make that recommended closure date binding, just as in SB 351.

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There are currently three large-bed ICF/MRs, two large-bed public ICF/MRs (KNI and Parsons) and one large-bed private ICF/MR (New Horizons).

By providing a date certain by which all large-bed ICF/MRs will be closed in Kansas, the Closure Commission and the Department of Social and Rehabilitation Services (SRS) can begin analyzing the gaps in waiver and other program services necessary, and they can have the time necessary to begin planning the transfer of funds from the institutional budget to the community services budgets, and to deal with any and all capacity issues to ensure the most integrated services to the former residents of large-bed ICF/MRs. Most importantly, doing this will allow time to work toward the closure of the three large-bed ICF/MRs and ensure that the proper services and supports are established.

**Millions of Dollars can Transfer to the Community to Eliminate the Waiting List** - KAPS would further recommend that every dollar saved by closing the large-bed ICF/MRs go directly as new dollars into community-based DD services. Closing all the large-bed ICF/MRs would allow millions of new dollars to flow into community based services. According to SRS, if all the persons served at KNI alone were served in the community, it would allow between \$8.7 million to \$12.5 million (all funds) to be transferred directly into community-based services (note: \$8.7 million is the figure if you assume 100% of the people at KNI were served at “super tier” rates, and \$12.5 million is the figure if you assume 100% are served at normal tier rates). Imagine how that \$8.7 million to \$12.5 million of additional funding for community-based DD services would grow if the state had a policy to close all of its large-bed ICF/MRs. Providing this funding would enable Kansas to establish the policy that would eliminate the HCBS DD waiting list. *In fact, we would also recommend that SB 351 be amended to establish this right to HCBS DD Waiver services and elimination of the waiting list in statute, and closure of the three large-bed ICF/MRs would be the mechanism to fund this policy.*

**Myth Busters:**

**“DD Institutions (public and private ICF/MRs) are an entitlement under Medicaid” = FALSE.**

- ICF/MRs are an optional service under federal Medicaid law (see attached information from CMS). Therefore, Kansas could have a policy to close all large-bed ICF/MR institutional beds and use the savings to provide millions and millions of new dollars for community-based services for Kansans with developmental disabilities. Closing all the large-bed ICF/MR

institutions would still allow Kansans with developmental disabilities to have access to small-bed ICF/MRs. More importantly, by transferring these dollars to community based services it would enable the promise of the DD Reform Act to become a reality.

**“Persons served in Parsons, KNI and large-bed ICF/MRs are vastly different than Kansans being served by the DD Waiver, and therefore could not survive in the community” = FALSE.**

- The Tier levels of persons being served in large-bed ICF/MRs when compared to the Tier levels of those being served in the community are strikingly similar. With these Tier levels, the lower the Tier number the greater the severity of the disability and greater the assistance needed. The higher the number, the lower the level of severity of the disability and the less assistance needed. In the three large-bed ICF/MRs, 48% are Tiers 1-2, while 52% are Tiers 3-5. In HCBS community DD Waiver services, 42% are Tiers 1-2 and 58% are Tiers 3-5. The numbers are even more similar and more telling when you compare the average Tier of those served in the different settings, as the following does:

KNI	2.0 Average Tier
Parsons	3.0 Average Tier
Private large-bed	3.1 Average Tier
Community Services	3.07 Average Tier

- The majority of individuals formerly served by the Winfield DD Institution are now successfully being served in the community. Few transferred to KNI or Parsons.
- Average Maladaptive Scores (0-200; higher the score, greater the severity of disability). KNI = 40.8; Parsons = 71.16; Private large-bed ICF/MR = 74.79; Community Services = 66.44.
- Average Adaptive Scores (0-500; higher the score, greater the severity). KNI = 399.83; Parsons = 209.70; Private large-bed ICF/MR = 227.95; Community Services = 210.73
- Average Health Score (0-30; higher the score, greater the severity). KNI = 11.57; Parsons = 7.8; Private large-bed ICF/MR = 7.72; Community Services = 8.31

In the landmark U.S. Supreme Court Olmstead case, the high court made it clear that persons with disabilities have the right to reside in the home and community of their choice in the most inclusive setting possible. Kansas has made progress toward that end, and this Committee has been key in that progress. KAPS urges you to continue to ensure that Kansans with developmental disabilities have the ability to live with dignity, independence and respect in the most integrated setting possible.

## Scope of Medicaid Services

Title XIX of the Social Security Act allows considerable flexibility within the States' Medicaid plans. However, some Federal requirements are mandatory if Federal matching funds are to be received. A State's Medicaid program *must* offer medical assistance for certain *basic* services to most categorically needy populations. These services generally include the following:

- Inpatient hospital services.
- Outpatient hospital services.
- Prenatal care.
- Vaccines for children.
- Physician services.
- Nursing facility services for persons aged 21 or older.
- Family planning services and supplies.
- Rural health clinic services.
- Home health care for persons eligible for skilled-nursing services.
- Laboratory and x-ray services.
- Pediatric and family nurse practitioner services.
- Nurse-midwife services.
- Federally qualified health-center (FQHC) services, and ambulatory services of an FQHC that would be available in other settings.
- Early and periodic screening, diagnostic, and treatment (EPSDT) services for children under age 21.

States may also receive Federal matching funds to provide certain *optional* services. Following are the most common of the thirty-four currently approved optional Medicaid services:

- Diagnostic services.
- Clinic services.
- **Intermediate care facilities for the mentally retarded (ICFs/MR).**
- Prescribed drugs and prosthetic devices.
- Optometrist services and eyeglasses.
- Nursing facility services for children under age 21.
- Transportation services.
- Rehabilitation and physical therapy services.
- Home and community-based care to certain persons with chronic impairments.

# Cross-System Comparison of Key Service Issues for DD Task Force Range Of Assessed Scores

Type Of Facility	Unduplicated Count	Maladaptive Score		Adaptive Score		Health Score	
		Min	Max	Min	Max	Min	Max
KNI	171						
Parsons	173	0.00	142.00	76.36	500.00	0.00	21.00
Large Bed ICF/MR	58	0.00	159.33	3.33	500.00	0.00	18.00
Medium Bed ICF/MR	93	0.00	153.33	0.00	412.53	1.00	15.00
Small Bed ICF/MR	126	0.00	162.00	59.90	500.00	0.00	22.00
Community Services	5807	0.00	167.33	104.95	500.00	1.00	20.00
		0.00	200.00	0.00	500.00	0.00	27.00

This report covers all adults who are HCBS waiver eligible (assessment converted score 35 or greater).

SRS Division of Health Care Policy  
Policy Evaluation, Research Training  
Monday, February 23, 2004

**DRAFT**



# Community Living Opportunities, Inc.

6900 W. 80th Street ▪ Overland Park ▪ Kansas ▪ 66204-3851 ▪ 913-341-9316 ▪ 913-341-7077 (fax)  
2113 Delaware Street ▪ Lawrence ▪ Kansas ▪ 66046-3149 ▪ 785-865-5520 ▪ 785-865-5695 (fax)  
[www.clokansas.org](http://www.clokansas.org)

Senate Ways & Means Committee

RE: SB531

March 2, 2004

Chairman Morris and members of the committee, thank you for the opportunity to testify today regarding SB531. My name is Stephanie Wilson. I am a Senior Administrator with Community Living Opportunities, Inc. a non-profit service provider that specializes in services for persons with severe to profound developmental disabilities. CLO has provided services for 26 years, and currently provides services to over 200 persons in five different CDDO regions.

CLO is a member of The Alliance for Kansans with Developmental Disabilities. Both CLO and The Alliance strongly support the ability of persons with developmental disabilities to live successful, fulfilling lives within the community. CLO, as well as other members of The Alliance, have greatly supported institutional closure efforts by arranging services for hundreds of persons placed out of Winfield State Hospital, Parsons State Hospital and KNI. We have had the privilege of seeing many of these persons develop personally satisfying, successful lives within their communities. We know how to serve persons with a vast range of developmental disabilities, including those with significant, challenging behavioral and medical needs.

Sadly, as we speak of our desire for Kansas to no longer have state institutions, we also have to talk about the current lack of capacity within our community service system to provide for the individuals remaining in the state hospitals. Again, the issue isn't knowledge of how to provide successful services, but rather inadequate funding for providing those services. Currently persons living within state hospitals have the choice of moving into community based services funded through the HCBS/MRDD waiver or within a private ICF/MR facility.

The current HCBS/MRDD waiver reimbursement rate for direct care staff is \$7.68 per hour. This amount is simply not enough to hire direct care staff to support more persons with developmental disabilities within the community. Direct care staff are leaving their positions to work at local fast food restaurants, and discount stores. Those who are dedicated enough to stay, frequently hold more than one job in order to make ends meet. To see how this crisis may impact any closure decision, one must only look to the current movement off of the developmental disability waiting list. Although SRS gave CDDOs the permission to utilize approximately \$3 million to place persons, many persons who were offered funding could not access services. Providers are not able to expand because they cannot hire direct care staff at the wages they are able to offer.

In addition, one of the key factors to the success of the closure of Winfield State Hospital was the availability of extraordinary funding, HCBS/MRDD special tier rates, for persons who have extraordinary needs. This funding has been placed at risk many times since the closure of Winfield, and is now utilized by SRS has more of a transitional funding mechanism rather than one which supports persons throughout their lives. SRS has developed a task force to look at this funding mechanism, however their work will likely not be complete until after the beginning of the new fiscal year. Both CLO and The Alliance encourage legislators to continue the existing proviso protecting extraordinary funding for those persons who receive it through FY05.

Regarding the choice of private ICF/MR services, the Governor's Budget Request includes a 10% reduction to ICF/MR funding rates. The 10% reduction in ICF/MR funding, if passed by the legislature, will be devastating to services for

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Executive Director ▪ Michael C. Strouse, Ph.D.

CLO's mission is to help people with severe developmental disabilities achieve personally satisfying, fulfilling lifestyles.

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consumers. CLO alone would lose approximately \$600,000 annually. The persons receiving ICF/MR service CLO are persons who have the most significant disabilities, and the greatest medical and behavioral needs. A majority of these persons were placed out of one of Kansas' state institutions, including several placed during the closure of Winfield State Hospital. The consumers and families from the Winfield State Hospital Closure were promised by state officials that they would continue to receive adequate funding for services within the community. As a result, agencies like CLO made a commitment to those families to provide adequate long term care for their family members. Now, six years later, funding for those services is at significant risk.

CLO and other ICF/MR providers have met with SRS. Attached is information SRS provided for us indicating how the 2.5% and 5% rate cuts would affect the cost coverage of small, medium and large ICF/MR facilities. As you will note, the current rates and the reductions actually cover the cost of the large facility to a greater extent than the small and medium size facilities. The implementation of the funding reduction in this fashion is inequitable, and reinforces services in large, more institutional, less community-based settings. We encourage legislators to restore ICF/MR funding for FY05. The amount of state funds needed to do this is a little less than \$1 million. This seems a small price to pay for protecting services to Kansans with the most severe to profound developmental disabilities, especially as we discuss serving more persons with similar disabilities out of state institutions.

Thank you for your consideration of the issues we have presented. I would be happy to try and answer any questions you may have.

## ICF-MR Rate/Cost Scenarios FY04-FY05

There are 280 persons served in Class II ICFs-MR

	Current State Plan FY04*	Freeze Current Rates FY04	2.5% Rate Reduction Effective 1/1/04	Freeze Rates in FY05***	FY05 Additional 2.5% Rate Reduction
Total (after Pt Liab/Vacancy) Budget	18,912,079.40	18,992,517.95	18,166,016.89	17,715,619.35	17,272,728.87
Difference	1,958,457.40	1,438,895.95	1,212,394.89	761,997.35	319,106.87
% Over Budget	11.55%	8.49%	7.15%	4.49%	1.88%
Average % Cost Covered					
Size A (Large)	100.00%	101.00%	99.73%	98.87%	96.40%
Size B (Medium)	98.02%	97.21%	95.59%	94.78%	92.41%
Size C (Small)	96.78%	93.00%	91.45%	90.67%	88.41%

\*Under the current State Plan, the costs are adjusted for inflation on October 1. The costs were increased by 2.5% and then the limits were applied. Limits were raised in order to have 75% of facilities being reimbursed at least 95%, as required by the State Plan.

### Reductions in Cost Due to Decreased Beds:

	Total # of Bed Closures	ICF-MR Rate Annualized	ICF-MR rate Annualized with Liability/ Vacancy applied	HCBS Rate Annualized	Difference
Bethpage-N	8	\$470,968.80	\$433,291.30	\$398,917.90	\$36,373.40
Bethpage-S	6	\$689,056.80	\$523,532.26	\$439,310.90	\$84,221.36
✓ **Terrace House	1	\$91,863.90	\$84,238.79	\$73,428.00	\$10,810.79
✗ Grandview Lane	4	\$342,165.20	\$314,791.98	\$293,712.00	\$21,079.98
	19		\$1,355,864.32	\$1,203,368.80	\$152,485.52

(Terrace House decreased from 5 beds to 4 in June 2003.)

\*\*\* Impact of Freezing Rates at reduced level for all of FY05

Kansas Department of

# Social and Rehabilitation Services

Janet Schalansky, Secretary

**Senate Ways and Means Committee**

March 8, 2004

**Senate Bill 531**

**Division of Health Care Policy**

Laura Howard, Deputy Secretary

785.296.3271

For additional information contact:  
Public and Governmental Services Division  
Tanya Dorf, Director of Legislative Affairs

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**Kansas Department of Social and Rehabilitation Services  
Janet Schalansky, Secretary**

Senate Ways and Means Committee  
March 8, 2004

**Senate Bill 531**

**Introduction**

Chairman Morris, I am Laura Howard, Deputy Secretary for Social and Rehabilitation Services. Thank you for the opportunity to provide testimony regarding Senate Bill No. 531 which would create the developmental disabilities institutions closure commission.

SRS operates two state hospitals for persons with developmental disabilities(DD), Kansas Neurological Institute (KNI) and Parsons State Hospital and Training Center (PSH&TC). These are the two institutions referenced in this bill. In coordination with 28 community developmental disability organizations (CDDOs), SRS also funds, regulates, monitors, and helps manage an array of community services for persons with developmental disabilities.

**Philosophy**

Kansas' philosophy in serving persons with DD is contained in the Kansas Developmental Disability Reform Act. The Act states that it is the policy of the state of Kansas to assist persons with DD by providing services and supports that increase their independence, productivity, integration, and inclusion in the community. As a result of implementing this policy and in response to the choices people and their families have made, Kansas has significantly increased the number of persons with DD served in community integrated settings. Other states which have pursued similar policies have demonstrated that, provided sufficient resources, all persons with DD can be successfully supported in the community.

**Senate Bill No. 531**

Senate Bill 531 creates within the Department of Social and Rehabilitation Services a nine member developmental disabilities institutions closure commission. The commission will provide a final report to the Governor by December 1, 2004 detailing recommendations for closing at least one of the developmental disabilities institutions and making recommendations regarding any changes in service delivery and funding to properly serve persons with developmental disabilities in the community.

Senate Bill 531 will directly impact the lives of 367 individuals with developmental disabilities currently living at KNI and PSH&TC and their families. Individuals and their families have chosen to receive services in the institutional setting as opposed to the community based setting. Whenever discussion of institutional closure arises the needs of these individuals and their families must be considered. This was the message that SRS received from the Interim Special

Committee on Appropriations/Ways and Means when they directed SRS to "create a task force that includes parents with children in mental retardation facilities, developmental disability advocates, and community partners to recommend alternative usage of existing intermediate care facilities for the mentally retarded (ICF/MR) and state developmental disability institutions and report to the 2004 Legislature by March 15, 2004." The work of that task force is not yet complete, but SRS can provide an update.

SRS convened the task force on February 4, 2004. Membership includes five parents of people with developmental disabilities, two professional advocates, and seven community service provider representatives (four of whom are also parents of people with developmental disabilities). The Task Force has met weekly and will continue to meet until the report is submitted March 15, 2004. The Task Force heard from a national representative on the issues of hospital closure nationwide as well as received information regarding the national trends in institutional closures. The discussions focus on the challenges of moving individuals from the institutional setting to the community including funding, medical services, dental care, housing and transportation. The recommendations of this Task Force could assist in any decisions made regarding the closure of an institution. While the work of this task force draws to a close, the recommendations may lead to a larger systems strategic planning process. This multi-year planning process would address the issues such as funding, housing, medical and dental care. SRS intends to take the recommendations made by the Task Force and move forward, with this broader system planning whether or not a closure commission is recommended by the legislature.

There are several points within Senate Bill 531 on which SRS would like provide comment:

\* **Commission membership**

The current bill provides for no individuals currently living at State hospitals or their family members on the commission. SRS would request that parents of individuals living at the institutions be added to the commission or at least offered the opportunity to present information to the commission. These individuals can assist in working through the challenges faced by moving individuals into the community.

\* **Savings**

SRS supports and encourages that any savings realized by the closure of any institution be redirected to community based services for individuals with developmental disabilities.

\* **Funding**

SRS supports the requirement that the funding follow the individuals into the community.

\* **Service and program changes**

SRS supports that the commission make recommendations on service and program changes to ensure that such supports continue at the community level to enable any potential closure recommendation. SRS continues to hear from families of individuals at the state institutions involves the inability of community services, as they are now, to support their family member. Their confidence in the availability of funding, medical care, dental care, behavioral supports and housing is low. The State must work to

develop the necessary community services to assure families that their loved one will receive the same level of care in the community as they have received in the institution. The State must address the issues of housing, medical care, dental care and availability of providers for future hospital closure to be successful.

The State of Kansas has been successful in the closure of state institutions in the past, including Norton State Hospital and Winfield State Hospital. SRS agrees that the timing is right to explore the need for and use of the current institutional settings in our state. SRS wishes to build on past successes. SRS believes that if a state institution closes as a result of this bill, it can happen successfully if sufficient time is given to work with individuals and their families to assist them in the transition process, while providing needed start up funds. Sufficient time becomes a factor when working with state employees affected by this change. In addition, sufficient time becomes necessary in regard to working with the community and providers to assure that high quality, comprehensive services are available to individuals and their families.

This concludes my testimony. Thank you for the opportunity to present information regarding Senate Bill 531. I will stand for questions.



March 2, 2004

TO: The Senate Ways and Means Committee  
FR: Tom Laing, Executive Director  
InterHab: The Resource Network for Kansans with Disabilities  
RE: Senate Bill 531; creating the developmental disabilities institutions closure commission.

InterHab offers conditional support for the process outlined in SB 531 to choose an institution for closure. The bill proposes significant policy deliberations, and makes a major effort at prescribing a process by which a closure discussion might be best held. The process outlined in the bill is a rational manner by which to answer the question, "If an institution is to be closed, which institution shall it be?"

Our cautionary tone in this matter is due to the far more complicated questions that SB 531 is not designed to answer, questions that are sufficiently complex to be an almost unfair assignment for the prescribed commission: i.e. the basic questions about the service environment in the community within which an effective closure plan can be successfully implemented

As to the timing of this proposal, I urge the committee to think seriously about initiating the issues next year, as opposed to this year, for these reasons:

Closure-related debates are complicated and dramatically emotional in the lives of persons served and their families/guardians, and in the lives of several hundred institutional staff and their supporting communities. Such discussions should be entered into advisedly, especially in the context of a Statehouse environment in which the cast will change, perhaps dramatically this fall, after which the policy inclinations of the legislature could also change dramatically. To ask incoming legislators in 2005, less than one month after their swearing in, to act on a matter of such gravity seems fraught with difficulty in which either the best plans could be rejected, or the worst plans adopted.

To prematurely initiate the "closure debate" may result in unnecessary feelings of dislocation and disorientation in the lives of the people most immediately impacted.

Finally, let me address the service environment with this question: Can community-based organizations withstand a new round of underfunded State expectations? The answer to that is:

**No, they cannot.**

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There is nothing in this bill that assures any greater State compliance with the DD Reform Act requirements for funding than has been present during the 8-plus year life of the Act ... i.e. the perennial unwillingness of SRS and the Administration to fully advise you and make appropriate recommendations to remedy the inadequacy of community reimbursement rates. During the life of the DD Reform Act, SRS has often acknowledged the challenge of providing community care with persistent low wages, but no recommendation has been forthcoming to you to increase those rates.

Persons living in institutions will not be well served if pushed into a community system that is already financially overstressed. If advocates and legislative leaders want to promote positive outcomes for persons who currently live in institutions, but who will one day be living in the community, they must first fix the foundations of the community system that will be asked to support those persons. A community system that has been allowed to erode. The costs of community services have the same upward pressure as State government, and private sector business. We must insist that the State respond to those needs at least as regularly as has been done for State workers' wages during many of the last several years. To do less and at the same time place more pressure on the community by closing institutions would be reckless.

Recommendation:

Given that SRS and community stakeholders have been meeting, at the direction of the interim report, to prepare findings for you as guidance on this very subject, I would recommend you hold this bill at least until after the SRS task force has issued its report, and allow those who are responsible for institutional programs (state officials), and those who will be responsible for persons moving to the community (community officials), to offer additional thoughts for you before you take action on this bill. I would further recommend you strongly consider a specific-focus interim discussion of the topic, and reintroduce this bill in the 2005 Legislative Session.

Attachment:

The attached policy paper for your consideration represents many hundreds of hours of discussions among InterHab members during recent months, and represents policy thoughts for your review prior to taking any action on institutional closure questions.

Taskforces both in both State and community circles are working to provide you with more comprehensive information that will also help you in your deliberations.

Thank you for your consideration of these thoughts.



## MR/DD Institution Policy Considerations

InterHab: The Resource Network for Persons with Disabilities

*The legislative discussions currently underway regarding institutional policies seem premised on a notion that institutional programs are distinct from other DD services. None of the discussions appear to view institutions in their proper perspective, i.e. a DD program in which significant resources are invested.*

*Though less than 10% of the state's DD service population lives in state DD institutions, the investment in funds, technical resources and facility space is disproportionately larger than that, and represents a considerable investment that should not be lost to the Kansas DD system.*

*Each institutional resource should be valued for what it currently offers, evaluated for how it can best be utilized, or how the resources may be reinvested in more appropriate ways.*

*The technical staff and the program resources they provide should be preserved.*

*Some bed space outside the traditional community-program must remain available for specialized needs –such as crisis placements or to meet emergency respite needs – for such needs are not currently funded in the DD community budget. Such beds as are needed can either be provided in the traditional state institutional setting, or perhaps a better approach would be to use available community capacity resources to enable a regional response across the state. Partnering with community resources – health care facilities and mental health care facilities – is an approach that should be considered.*

*All remaining funds should be viewed as a source for enhancing reimbursement rates for community providers, which will increase community wages and training to improve recruitment and retention of these critically needed workers.*

*In short, closure discussions need to include the official recognition that “closure” is forever. So, discussions need to include the acknowledgement of the permanent loss of a system resource. The fact that institutions are not currently managed as a flexible part of an overall service menu is not automatically an argument for closure, but for better management.*

*In addition to a thorough review of past studies which examined closure experiences, the following thoughts arise from discussions with various community service providers and CDDOs:*

1. Recommendations for closure/consolidation should not be entertained prior to receipt of a comprehensive report from SRS and the Community regarding:

- ✓ The demographic profile of those in the respective institutions, with a specific and detailed assessment of the nature of service and support needs of the persons currently served at KNI and PSHTC, as well as the identification of the prevalence of instances in which persons served in institutions are a threat to themselves or others.
- ✓ A detailed cost assessment of planning and executing out-placements, as well as meeting ongoing service needs.

2. All planning and implementation of eventual closure or consolidation plans should be done in adherence with statutory consumer protection and financing provisions of the DD Reform Act.

3. All savings derived from institutional closure/consolidation must be reserved for enhancements to community services and supports. Investments should be made with savings to make community services as stable as has been the case in institutional settings (where state investments have routinely kept wages adjusted to assure a stable work force.)

4. The most critical consideration is the basic right of a person with disabilities living in an institution (and their families and guardians) to be fully informed of choices available in their home community, or if no home community is easily identified, the community where family members or other important persons in their lives are located, and where needed services can be secured.

5. Consideration should be given to address management and administrative needs for closure/consolidation activities by use of an *ad hoc* staff team drawn from state and community staff outside of the staff at the respective institutions facing closure/consolidation.

6. Given the large number of persons remaining in state institutions who also have mental illness diagnoses, assurances must be developed that the community mental health system is equipped, and will respond, to this influx of persons with specialized MH needs. Additionally, efforts to strengthen enforcement of agreements with CMHCs will help provide better care coordination for such individuals. Enhanced training for MH professionals on DD issues will also improve the quality of care.

7. In addition, as Legislators consider direction setting for any evaluation of institutional policies:

- ✓ Recognize that decreased community financial capacity due to chronic underfunding has weakened the system's ability to fill financial gaps.
- ✓ Consider maintaining state investment in specialized institutional professional resource by partnering with regional university or other community professional human resource infrastructures.
- ✓ Address existing community resource gaps, such as medical, dental, transit and housing, and develop solutions to those ancillary service challenges.

Recognize that two key issues that legislators will face – economic impacts on state workers and on communities -- should not be addressed using resources from the SRS budget, but through more appropriate budgets, such as the departments of Human Resources and Commerce. SRS funds must not be diverted from their proper purpose, to finance the needs of the persons served.



# Families Together, Inc.

## Parent Training & Information Centers for Kansas

Home Page:  
<http://www.familiestogether.org>

Wichita Parent &  
Administrative Center  
3033 W. 2<sup>nd</sup>, Suite 106  
Wichita, KS 67203  
Voice/TDD (316) 945-7747  
1-888-815-6364  
Fax (316) 945-7795  
[wichita@familiestogetherinc.org](mailto:wichita@familiestogetherinc.org)

Topeka Parent Center  
501 Jackson, Suite 400  
Topeka, KS 66603  
Voice/TDD (785) 233-4777  
1-800-264-6343  
Fax (785) 233-4787  
[topeka@familiestogetherinc.org](mailto:topeka@familiestogetherinc.org)

Garden City Parent Center  
111 Grant  
Garden City, KS 67846  
Voice/TDD (620) 276-6364  
1-888-820-6364  
Espanol (620) 276-2380  
Fax (620) 276-3488  
[gardencity@familiestogetherinc.org](mailto:gardencity@familiestogetherinc.org)

Kansas City Parent Center  
6811 W. 63<sup>rd</sup> St., Suite 117  
Overland Park, KS 66202  
Voice/TDD (913) 384-6783  
1-877-499-5369  
Fax (913) 384-5887  
[kansascity@familiestogetherinc.org](mailto:kansascity@familiestogetherinc.org)

Statewide Spanish Parent Line  
1-800-499-9443

Mr. Chairman, Members of the Committee, I am writing in support of Senate Bill 531. I write both as an employee of Families Together, Inc. and as a sibling of a young man who had severe physical disabilities.

Families Together, Inc. is the parent training and information center for the state of Kansas. Our duties are to assist families that include sons and daughters with disabilities through consultation, referral, and training services. As parents and family members of individuals with disabilities, we are dedicated to a society that includes and values *all* persons. We passionately believe that families and children should have the supports and services they need to be successful in this endeavor. We believe that children and adults with disabilities have the right to be included in their schools, workplaces, and communities. These values cannot be realized as long as a segment of our population is "warehoused" in institutions. Families Together, Inc. wholly supports the closure of the remaining state hospitals.

My brother, Randy, was born 12 months and 12 days after me in 1967. I do not remember my life without disability. It never made sense to me that perhaps, some people in our communities were thought of differently or as not having as much value as others, simply because they had a disability. I clearly remember my mother and I speaking of the subject of institutionalization for Randy. It was a subject that was spoke of only twice in our home in 27 years. On both occasions, it was clearly not an option. My mother and I agreed that the **ONLY** place for Randy was in our family home with his parents and sibling. We were adamantly opposed to any other option. This was long before waivers and case management. We were prepared to do whatever it took to keep my brother with us. When my brother became an adult, community living was still the only option. Adult services were scarce and of mediocre quality at best. Several years later, my brother was one of the first persons in Kansas to be served on an Home and Community Based Waiver.

Both as an employee of Families Together, Inc. and as a sibling, I support Senate Bill 531. I have had the privilege to read Ms. Rhys' testimony and agree with the plan outlined, giving adequate time for the planning of the hospital closures, by an independent agent. I strongly support the use of saved monies to serve persons in communities. This is a fiscally responsible way to spend State funds. But more importantly, it is the right thing to do-- the ethical thing to do. All people belong-- all people are valued. Thank you for taking the time to read my testimony and I hope you favorably pass SB 531.

Darla Nelson-Metzger

*Assisting Parents and Their Sons and Daughters with Disabilities*

Senate Ways and Means  
3-8-04  
Attachment 13

Testimony of:

Sheriff Lynn C. Myers  
Johnson County Sheriff's Office  
Olathe, Kansas 66061  
(913) 791-5805

House Bill #2725

Senator Steve Morris, Members of the Senate Ways and Means Committee,

My name is Lynn C. (Currie) Myers and I am the Sheriff of Johnson County Kansas. I am appearing before you today in support of HB2725 that will allow for the collection of a per diem from prisoners who have been committed to the custody of the Sheriff.

Prisoners who have been convicted of a crime should be expected to reimburse the taxpayers of the county a small portion of the cost that it takes to house and care for prisoners. Currently it costs the taxpayers of Johnson County \$112.17 per day to house a prisoner in one of my detention facilities. Would charging a per diem fee of \$5.00 or \$10.00 be unreasonable compared to the costs the taxpayers must currently bear? I would answer no. The practice of charging a prisoner per-diem fee is already in place in sixteen states and not an untried concept.

Collecting the per diem accomplishes two objectives that will have an impact on the prisoner and the county. First, the prisoner experiences the financial implications that accompany criminal behavior and that can serve as a deterrent for future criminal activity. Second, the county recoups some expenses from individuals who are directly using the services.

House Bill #2725 allows local control over the amount of fee that can be collected and also contains important safeguards. By prioritizing restitution, any child support owed, or court costs or fines must be paid before the per diem is collected. The bill also provides for a reduction or waiver of the amount in instances in which an undue hardship would be created if the per diem were collected. It is not my intention to make attempts to collect money from those who are not in a position to pay. The costs of such a venture would quickly outweigh the benefit.

In closing, I would like to thank you for the opportunity to speak to you this afternoon and I ask that you support House Bill 2725. I will be happy to answer any questions you may have.

Senate Ways and Means  
3-8-04  
Attachment 14



**KANSAS**  
ASSOCIATION OF  
**COUNTIES**

WRITTEN TESTIMONY  
Before the Senate Ways and Means Committee  
HB 2725  
March 8, 2004

By Judy A. Moler, General Counsel/Legislative Services Director

Thank you Chairman Morris and Ways and Means Committee for allowing the Kansas Association of Counties to provide written testimony on HB 2725.

The Kansas Association of Counties supports HB 2725. The passage of HB 2725 would allow the board of county commissioners in each county to pass a resolution, if they so choose, to recover costs from certain inmates in county jail. The inmates affected would be those housed in the county jail prior to and after a conviction of a crime. The fees would be applied to the county's daily cost of housing an inmate.

Increasingly counties are looking for ways in which to balance the budget in a fiscally responsible manner. This would be one tool in their tool box. For this reason, the Kansas Association of Counties respectfully requests that the committee pass favorably HB 2725.

The Kansas Association of Counties, an instrumentality of member counties under K.S.A. 19-2690, provides legislative representation, educational and technical services and a wide range of informational services to its member counties. Inquiries concerning this testimony should be directed to Randy Allen or Judy Moler by calling (785) 272-2585.

6206 SW 9th Terrace  
Topeka, KS 66615  
785•272•2585  
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email kac@ink.org

Senate Ways and Means  
3-8-04  
Attachment 15

**Testimony on establishing the water supply storage assurance fund;  
establishing the local water project match fund**

to

**The Senate Ways and Means Committee**

**SB 527**

**by Ken Grotewiel  
Assistant Director  
Kansas Water Office  
March 8, 2004**

Good morning, Senator Morris and members of the Committee. I am Ken Grotewiel, Assistant Director of the Kansas Water Office. I am pleased to be here this morning to testify in support of SB 527.

The purpose of SB 527 is to formalize in statute the creation of two funds which have been authorized for several years by appropriation provisos.

**Water Supply Storage Assurance Fund**

Creation of this fund will allow for the receipt of water assurance district payments from assurance districts. This bill is necessary for the agency to receive and expend monies in accordance with it's obligations under the Water Assurance Act. The water supply assurance fund was statutory until 1998 when it was inadvertently abolished.

Money could be expended from this fund for the following purposes:

- 1) Payment to the federal government for annual capital costs of water supply storage in federal reservoirs under the water assurance program;
- 2) Payment and reimbursement to the water marketing fund for water supply storage space previously paid for with revenue from the water marketing fund;
- 3) Payment to the federal government of annual operations, maintenance and repair costs associated with water supply storage space; and
- 4) Payment and reimbursement to the water marketing fund and state general fund for costs incurred by the state for administration and enforcement of the water assurance program.

The Kansas Water Office has routinely conducted these transactions since the creation of the Water Assurance Program.

**Local Water Project Match Fund**

Creation of this fund would allow the Kansas Water Office to receive funds from local government entities and instrumentalities, which could then be use used to match state and federal funds that have become available for water projects.

Thank you for your time and attention today. I am happy to stand for questions.

*Senate Ways and Means  
3-8-04  
Attachment 16*