Kansas Legislative Research Department December 30,

# MINUTES

## JOINT COMMITTEE ON HOME AND COMMUNITY BASED SERVICES OVERSIGHT

October 14, 2009
Room 143-N—Statehouse

### Members Present

Senator Carolyn McGinn, Chairperson
Representative Bob Bethell, Vice-chairperson
Senator Laura Kelly
Senator Kelly Kultala
Senator Dwayne Umbarger
Representative Jerry Henry
Representative Peggy Mast

### Members Absent

Representative Brenda Landwehr
Representative Melody McCray-Miller

### Staff Present

Terri Weber, Kansas Legislative Research Department
Amy Deckard, Kansas Legislative Research Department
Reed Holwegner, Kansas Legislative Research Department
Estelle Montgomery, Kansas Legislative Research Department
Doug Taylor, Office of the Revisor of Statutes
Nobuko Folmsbee, Office of the Revisor of Statutes
Jan Lunn, Committee Secretary

### Conferees

Don Jordan, Secretary, Kansas Department of Social and Rehabilitation Services
Ray Dalton, Deputy Secretary, Kansas Department of Social and Rehabilitation Services
Martin Kennedy, Acting Secretary, Kansas Department on Aging
Kathy Lob, Legislative Liaison, Self-Advocate Coalition of Kansas
Jane Rhys, Executive Director, Kansas Council on Developmental Disabilities
Rocky Nichols, Director, Kansas Disability Rights Center
Tom Laing, Executive Director, InterHab

## Others Attending

See an attached list.

## Morning Session

Chairperson McGinn called the meeting to order at 10:05 a.m. and welcomed those attending. Senators, Representatives, staff, and members of the public introduced themselves.

Terri Weber, Legislative Research Department, described the charge of the Joint Committee on Home and Community Based Services (HCBS) Oversight to include: (a) helping to ensure a comprehensive and coordinated system of providing long-term care services (including home and community-based services) to Kansas residents; (b) overseeing the savings resulting from the transfer of individuals from state or private institutions to home and community-based services; and (c) ensuring that any proceeds resulting from the successful transfer are applied to the system for providing long-term care and home and community based services. Additionally, the Committee is to review and study other components of the state's long-term care system (Attachment 1). Ms. Weber also reviewed the statutory requirements (KSA 39-7,159; 39-7,160; 39-7,161; and 39-7,162) defining the coordinated system; the Money Follows the Person program (MFP); the agencies responsible for system implementation and their roles; Joint Committee membership, terms of service, and reporting relationships; as well oversight responsibilities related to specific information and data (Attachment 2). Ms. Weber also distributed the "Report of the Joint Committee on Home and Community Based Services Oversight to the 2009 Kansas Legislature" (Attachment 3) for review by members.

Amy Deckard, Legislative Research Department, was recognized to present information on the current funding and status of HCBS waivers. Ms. Deckard distributed a spreadsheet entitled "Home and Community Based Services Waivers (HCBS) from all funding sources FY 2000 to FY 2011 Agency Request" (Attachment 4). Chairperson McGinn questioned whether information contained in this spreadsheet included community developmental disabilities (DD) programs. Ms. Deckard clarified that the spreadsheet excludes community DD funding; Chairperson McGinn asked that total funding for community DD programs, not just waiver funding, be presented at the next meeting. Representative Bethell noted that the Department of Social and Rehabilitation Services (SRS) requested fewer total dollars in FY 2011 than is estimated for FY 2010 while dollars within the DD waiver category increased in FY 2011; he requested clarification and asked whether the American Recovery and Reinvestment Act of 2009 (ARRA) funding impacted the dollars contained in the spreadsheet. Social and Rehabilitation Services Secretary Don Jordan responded that total agency funds requested are the best estimates of the waivers at the current time, and that the FY 2010 and FY 2011 estimates exceeded appropriations. In order to cover the shortfall, available fee funds were shifted within SRS and the state hospitals, freeing up state funding to support projected waiver spending in FY 2010. SRS worked with the Division of the Budget to bring in additional Title XIX funds for projected FY 2011 waiver spending to eliminate any negative impact on beneficiary services. These transferred dollars are referred to as "enhancements" and can be seen in the column entitled "FY 2011 Agency Enhancements." He clarified that much of the difference in requested total dollars comes from the physical disability (PD) waiver policy requiring that for every two individuals coming off the waiver, one individual is added. ARRA funding is provided from October 2009 through December 2010 and thus would impact only half of FY 2011 total agency dollars requested by SRS. Members attending discussed the information provided, and

Representative Henry requested that further discussion of requested SRS budgeted "enhancements" occur at the next meeting including additional detail on what is the "enhancement."

Ms. Deckard distributed another spreadsheet, "Home and Community Based Services Waivers (HCBS) from the State General Fund FY 2008 to FY 2011 Agency Request" (Attachment 5). Ms. Deckard noted the increase in the Federal Medical Assistance Percentage (FMAP) rate for the Kansas Medicaid program was increased in October 2009 due to federal ARRA funds. A chart, "HCBS Waivers FY 2009 Expenditures from All Funding Sources" (Attachment 6) was reviewed and discussed.

Estelle Montgomery, Legislative Research Department, distributed a handout, "10 Year State Hospital Average Daily Census" (Attachment 7), and discussed variances in the trend for the period. State Mental Hospitals include Osawatomie State Hospital, Rainbow Mental Health Facility, and Larned State Hospital. Developmental Disabilities Hospitals include the Kansas Neurological Institute and Parsons State Hospital and Training Center. Ms. Montgomery also discussed (Attachment 8) the Governor's Facilities Closure and Realignment Commission and its charge to evaluate the closure and realignment of state facilities and alternative uses of such facilities. Ms. Montgomery noted the interest of KVC Behavioral HealthCare (KVC) in the Rainbow Mental Health Facility building and the impact of possible closure of Parsons or KNI. Also discussed were potential challenges and concerns related to hospital closure and the complexity experienced with the closure of Winfield Sate Hospital in 1998. Representative Bethell inquired about the stability of sexual predators in phase 6 of treatment at Larned State Hospital. Ms. Montgomery indicated that this population fluctuates, and she deferred to Secretary Jordan for additional clarification. Secretary Jordan responded that fluidity relative to this population is predictable. Senator Kelly asked about the definition of "phase 7" in the sexual predator treatment program, how many individuals are in this phase and where they are located. In addition, Senator Kelly inquired about the differences in cost effectiveness for each phase of transition within the program. Secretary Jordan reported that phase 7 is defined as conditional release to the community and currently, there are two individuals in that particular phase. Secretary Jordan will provide the location of those two individuals at the next meeting as well as cost per phase information. Senator Kultala asked whether Rainbow Mental Health Facility is at capacity. Ms. Montgomery clarified that Rainbow currently is at seven percent above capacity. Senator Kultala requested information regarding KVC's role at the Rainbow facility. Ms. Montgomery indicated that when Rainbow Mental Health Facility ceased performing children and adolescent admissions, KVC assumed responsibility for that function. Senator Kultala followed with a question related to whether a contract for these services was released for bid. Secretary Jordan reported that a request for providing these admitting services was released in 2007, however, KVC was the only organization expressing interest which resulted in a sole source contract. Since that time, others agencies have expressed interest in providing similar services, and a Request for Proposal (RFP) was released for Larned State Hospital Children's Care Program. Secretary Jordan indicated there is a process in place for obtaining a sole source contract when there is no competitive market for required services.

Reed Holwegner, Legislative Research Department, presented information related to an advance notice of proposed amendments to Section 1915 (c) of the Federal Social Security Act which would impact certain Medicaid requirements for HCBS Waivers. Mr. Holwegner indicated the purpose of the amendment is to remove a current regulatory barrier which would allow states to design waivers based on needs rather than on diagnosis or condition, and to define better the terms "home" and "community" (Attachment 9). Members attending discussed the ramifications of the proposed amendments.

Chairperson McGinn recognized Secretary Don Jordan, SRS, to present HCBS waiver information (Attachment 10). Secretary Jordan defined Medicaid waivers as federally approved requests to waive certain specified Medicaid rules. For example, Medicaid rules allow states to draw down federal Medicaid funds for severely disabled persons (eligible for institutional placement) who live in the community and who are served by community supports and services (not covered under the regular Medicaid program). These HCBS waivers are required to be less than or equal to the cost of serving people in comparable institutions. Secretary Jordan discussed the differences among the:

- Developmental Disability Waiver (MR/DD);
- Physical Disability Waiver (PD);
- Traumatic Brain Injury Waiver (TBI);
- Technology Assisted Waiver (TA);
- Serious Emotional Disturbance Waiver (SED);
- Autism Waiver; and
- Money Follows the Person Grant (MFP).

Secretary Jordan commented on collaboration with the Kansas Department on Aging to identify individuals for potential transition from an institutional environment into the community, to develop benchmarks, and to implement strategies to effectively operate the HCBS Waiver program.

Considerable discussion was heard related to the number of individuals on waiting lists; the number who advance to a waiver that are deemed to be in "crisis" and the impact of crisis funding on various waivers. Discussion followed on cost differences between tiers of service for those on waivers; the possibility of a sliding fee scale for the Autism Waiver; the number of individuals waiting for Autism Waiver services and whether they would "age out" before receiving services; audits of PD Waiver and the results of such audits; and reporting processes for SRS audit information and consequences for facilities noncompliant with rules and regulations. Parental fees for various waiver services; the movement within DD hospitals; and the question of whether youth eligible for SED services remain in their own home or a foster home rather than being admitted to a state psychiatric facility also were discussed.

Senator Kultala asked Secretary Jordan whether CMS rules specify services provided through HCBS waivers are at average rates less than or equal to national institutions or Kansas institutions. Secretary Jordan clarified average rates are determined by comparable Kansas institutions. Senator Kultala asked for what length of time is the MFP demonstration grant. Secretary Jordan responded the grant is for a time period of five years, and Kansas is in the second year of implementation. Senator Umbarger inquired whether individuals on the PD Waiver waiting list are increasing or decreasing at the current time. Secretary Jordan replied that the waiting list is increasing. Following discussion on Secretary Jordan's testimony, Committee members asked questions or requested additional information (listed below) from SRS that require follow-up at the next meeting.

- Describe how "crisis" is defined? What consequences would occur if funding is insufficient to meet demand for crisis services, *e.g.*, would an individual go back to a state institution? Is there a possibility there could be a shortfall in funding for crisis services? Provide a historical presentation of crisis services, *i.e.*, numbers and dollars.

- Define tier funding and movement between the tiers. In addition, provide the average cost for each tier and the range for each tier.

- Recently, SRS audited local Centers for Independent Living (CILs) providing PD Waiver services. Provide a report on SRS findings and actions taken relative to such findings.

- Provide a detailed report on the Autism Waiver on an annual basis (*i.e.*, growth rate, youth ineligible for services due to aging out).

- Provide specific information on parental fees for waiver services. For example, on which waivers do parents contribute a fee, what is the fee structure for each waiver, why the Autism waiver excludes a parental fee and will SRS implement a fee. If a parental fee is implemented, what state statutes, regulatory rules, and policy changes are required, and provide a status report on the federal (CMS) review of the Kansas parental fee policy.

Chairperson McGinn recessed the meeting at 12:05 p.m. and announced the meeting would reconvene promptly at 1:20 p.m.

## Afternoon Session

Chairperson McGinn reconvened the meeting at 1:23 p.m. and introduced Martin Kennedy, Acting Secretary, Kansas Department on Aging (KDOA), to present his report on the State's Frail Elderly (FE) waiver program.

Mr. Kennedy defined the HCBS FE Waiver program as serving seniors age 65 and older; the client must be functionally eligible for the level of care delivered by a nursing facility and must meet Medicaid financial eligibility requirements. He described the program's point of entry, services offered, and long-term care expenditures (Attachment 11). Statistical information regarding case load, Medicaid monthly expenditures, and long-term care expenditures was discussed. Mr. Kennedy reported that at the current time there is no waiting list for the FE Waiver but expenditure monitoring continues. He described two FY 2011 budgeted HCBS FE enhancements for maintenance of effort in anticipation of an increased caseload and the use of telehealth services to assist in monitoring chronic illness. Mr. Kennedy provided information on the pilot telehealth project in southeast Kansas (Windsor Place) which monitors chronic illness for a small population of Kansas seniors, and the findings being collated, analyzed, and reported by the University of Kansas (KU).

Considerable discussion was heard regarding telehealth, technology opportunities, and the cost savings and cost avoidance of keeping Kansas seniors out of nursing facilities.

Senator Kelly questioned whether information is available to show the effectiveness of the pilot project, how participants are selected for the program, and how results are validated. Bill McDaniel, KDOA, was present and clarified that the study being conducted is not a controlled study and includes a small population for whom inpatient hospital admissions are being tracked and compared to a pre-study hospital admission baseline.

Senator Kelly expressed concern that studies such as the one described tout dollar savings without valid results documenting the reality of any cost savings or avoidance. Mr. McDaniel responded that KU should have the findings report within the next two to three months; it will be forwarded to Committee members.

Chairperson McGinn asked how Windsor Place and KU were selected to participate in the study. Mr. Kennedy responded that Windsor Place has had an active interest in this project for several years, and KU has invested heavily in a telehealth system within its information technology and medical school departments. Representative Mast requested that Mr. Kennedy encourage KU to apply for any available grant funding in order to advance technology integration into the health sciences.

Chairperson McGinn recognized Ray Dalton, SRS, Deputy Secretary, who distributed information summarizing long-term care by DD institutional settings, DD waiver services, FE/PD/TBI institutional settings, and FE/PD/TBI community services (Attachment 12). Information included numbers of individuals being served, average cost per person, and estimated costs (all funds compared to state general funds). Under the DD institutional setting, it was noted there were 21 new admissions in public intermediate care facilities with mental retardation (Public ICFs/MR).

Representative Bethell asked the reason for those admissions and where the 21 clients were placed. In addition, he asked if those individuals were on waiver services before admission. Mr. Dalton clarified that the difficulty in finding providers, behavioral challenges, and medical issues are reasons for admissions. Secretary Jordan responded that of the 21 admissions, 17 went to Parsons State Hospital and four were admitted to KNI. Mr. Dalton will report at the next meeting whether the 21 clients were on waivers prior to admission.

Kathy Lobb, Legislative Liaison, Self Advocate Coalition of Kansas, was introduced by Chairperson McGinn. Ms. Lobb shared her experience as a young individual schooled in an institution, and she described her successful transition from the institutional environment into the community. Ms. Lobb advocated for the closure of state hospitals to provide opportunities to serve individuals on HCBS waivers within the community (Attachment 13).

Jane Rhys, Ph.D., Executive Director, Kansas Council on Developmental Disabilities, was recognized to present recommendations for cost-neutral funding of DD waivers in Kansas (Attachment 14). Dr. Rhys provided an overview of her agency's structure and mission. Discussion was heard regarding the lack of resources required to serve Kansans eligible for DD waiver services. The proposal supported by the Council is to close one or both remaining state hospitals for individuals with developmental disabilities and to serve those under- and unserved Kansans on the DD waiver waiting list with the funds appropriated for these institutional facilities. Dr. Rhys was involved with the closing of Winfield State Hospital in 1998, and she discussed that experience with Committee members. She described the processes and methods used in the hospital closure, and provided documentation of improved outcomes for residents and documentation of reduced public costs resulting from the closure. In addition to the testimony provided, a Final Report of the Hospital Closure Project 1998 submitted by Dr. James Conroy was provided to Committee members (Attachment 15).

Representative Bethell noted that some Closure Commission members are concerned about the disposition of a group of individuals at Parsons Mental Health Facility who have committed sexual crimes and have not been adjudicated. Representative Bethell asked whether, in other states, individuals who could be classified as sexual predators but never adjudicated have been placed in group homes. Dr. Rhys will make an inquiry and report back to the Committee at the next meeting. Senator Kelly inquired whether there was a DD waiting list at the time Winfield was closed and whether historical information existed relating to waiting list decreases. Dr. Rhys will follow up at the next meeting.

Chairperson McGinn called on Rocky Nichols, Director, Kansas Disability Rights Center of Kansas. Mr. Nichols spoke in favor of closing "expensive, out-of-date, large-bed DD institutions (KNI and Parsons) and serve the needs of people with DD in community-based settings" (Attachment 16). Mr. Nichols responded to Senator Kelly's question regarding persons on waiting lists during the period of time Winfield was closed. He referred to a graphic illustration entitled, "Number of Persons Waiting," contained in his testimony that provides a historical trend analysis for adults and families on waiting lists from FY 1994 through FY 2004. As shown, the lowest point for persons waiting was 1997 and 1998 which was during the period of the Winfield closure. Mr. Nichols testified that of the five states surrounding Kansas, Oklahoma spends approximately 50 percent more per person per year on individuals under HCBS DD waivers.

Senator Kelly requested that Mr. Nichols report back at the next meeting regarding information comparing HCBS DD Waiver spending and services provided by Kansas and Oklahoma. Mr. Nichols reported there are 12 states who have closed public and private institutions with beneficial outcomes and positive results from redirecting funding to services covered under HCBS DD waivers.

Senator Kultala inquired which 12 states have closed public and private DD institutions, whether there was existing data to substantiate waiting lists decreases, what cost savings resulted from institution closure (especially to the State), and whether savings were redirected to existing HCBS programs. Mr. Nichols will provide that information at the next meeting.

Chairperson McGinn called on Tom Laing, Executive Director, InterHab, who asked Committee members to examine the system of services for persons with developmental disabilities as one system within which community and institutional programs are offered (Attachment 17). The one system can then be evaluated to ensure efficient and effective operations in serving the most people possible. He encouraged Committee members to study the range of costs per tier of service for both DD institutions and those being served under HCBS waivers.

Chairperson McGinn asked Terri Weber to review the recommendations submitted by the Joint Committee on Home and Community Based Services Oversight to the 2009 Kansas Legislature (see Attachment 3 noted previously). Ms. Weber also reviewed the list of follow up items for discussion at the meeting scheduled for November 19 and 20. Chairperson McGinn asked Committee members to contact Terri Weber if there are other questions that inadvertently may have been excluded from her verbal review.

During the afternoon session of the meeting, Ms. Montgomery and Ms. Deckard distributed two additional resources: "Home and Community Based Services Waiting List" (Attachment 18) and "Department of Social and Rehabilitation Services FY 2010 Items Covered Internally" (Attachment 19). These spreadsheets were used as an adjunct to other statistical information provided by staff and conferees.

Chairperson McGinn adjourned the meeting at 4:08 p.m.

Prepared by Jan Lunn
Edited by Terri Weber

Approved by Committee on:

November 20, 2009
(Date)

**JOINT COMMITTEE ON HOME AND COMMUNITY BASED OVERSIGHT**

**October 14, 2009**

**Sign In**

| | |
|---|---|
| Anne Marie Hughey | SKIL |
| Craig Kaberline | K4A |
| Ray Dalton | SRS |
| Suzanne Wikle | KAC |
| SEAN MILLER | CAPITOL STRATEGIES |
| Barb Conant | KDOA |
| Mike Hutfles | CLO |
| Patrick Woods | SRS |
| Mary Ellen Conlee | Conlee Consulting |
| | Craig Resources |
| Richard Giblin | Craig |
| Monte Coffman | Windsor Place |
| | DISABILITY RIGHTS CENTER |
| Mitzi E. McFatrich | KS Advocates for Better Care. |
| TOM LAING | InterHab |
| Rocky Nichols | DRC Kansas |

*Current as of:* Septembe 2009

# 2009 JOINT COMMITTEE ON HOME AND COMMUNITY BASED SERVICES OVERSIGHT

| Senate | House |
|---|---|
| Sen. Carolyn McGinn, Chairperson | Rep. Bob Bethell, Vice-Chairperson |
| Sen. Laura Kelly | Rep. Jerry Henry |
| Sen. Kelly Kultala | Rep. Brenda Landwehr |
| Sen. Dwayne Umbarger | Rep. Peggy Mast |
|  | Rep. Melody McCray-Miller |

**Kansas Legislative Research Department**

Terri Weber, Reed Holwegner, Amy Deckard
Jan Lunn, Committee Secretary

**Revisor of Statutes Office**

Doug Taylor, Nobuko Folmsbee

## CHARGE

To help ensure that long-term care services, including home and community based services, are provided through a comprehensive and coordinated system throughout the state, the Committee is to oversee the savings resulting from the transfer of individuals from state or private institutions to home and community based services and to ensure that any proceeds resulting from the successful transfer be applied to the system for the provision of services for long-term care and home and community based services. Additionally, the Committee is to review and study other components of the state's long-term care system.

Joint Home and Community Based Services
Date: 10/14/09
Attachment: 1

**Kansas Legislature**

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## 39-7,159

### Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE

### Article 7.--SOCIAL WELFARE

**39-7,159. Comprehensive and coordinated system of long-term care services; cooperation by department on aging, SRS and Kansas health policy authority.** (a) In the state of Kansas, long-term care services, including home and community based services, shall be provided through a comprehensive and coordinated system throughout the state.

(b) The system shall:

(1) Emphasize a delivery concept of self-direction, individual choice, home and community settings and privacy;

(2) ensure transparency, accountability, safety and high quality services;

(3) increase expedited eligibility determination;

(4) provide timely services;

(5) utilize informal services; and

(6) ensure the moneys follow the person into the community.

(c) All persons receiving services pursuant to this section shall be offered the appropriate services which are determined to be in aggregate the most economical available with regard to state general fund expenditures. For those persons moving from a nursing facility to the home and community based services, the nursing facility reimbursement shall follow the person into the community.

(d) The department on aging, the department of social and rehabilitation services and the Kansas health policy authority shall design and implement the system, in consultation with stakeholders and advocates related to long-term care services.

(e) The department on aging and the department of social and rehabilitation services, in consultation with the Kansas health policy authority, shall submit an annual report on the long-term care system to the governor and the legislature annually, during the first week of the regular session.

**History:** L. 2008, ch. 168, § 1; July 1.

Joint Home and Community Based Services
Date: 10/14/09
Attachment: 2

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## 39-7,160

### Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE

### Article 7.--SOCIAL WELFARE

**39-7,160. Joint committee on home and community based services oversight; members; meetings; compensation and expenses.** (a) There is hereby established the joint committee on home and community based services oversight. The joint committee shall review the number of individuals who are transferred from state or private institutions and long-term care facilities to the home and community based services and the associated cost savings and other outcomes of the money-follows-the-person program. The joint committee shall review the funding targets recommended by the interim report submitted for the 2007 legislature by the joint committee on legislative budget and use them as guidelines for the future funding planning and policy making. The joint committee shall have oversight of savings resulting from the transfer of individuals from state or private institutions to home and community based services. As used in K.S.A. 2008 Supp. 39-7,159 through 39-7,162, and amendments thereto, "savings" means the difference between the average cost of providing services for individuals in an institutional setting and the cost of providing services in a home and community based setting. The joint committee shall study and determine the effectiveness of the program and cost-analysis of the state institutions or long-term care facilities based on the success of the transfer of individuals to home and community based services. The joint committee shall consider the issues of whether sufficient funding is provided for enhancement of wages and benefits of direct individual care workers and their staff training and whether adequate progress is being made to transfer individuals from the institutions and to move them from the waiver waiting lists to receive home and community based services. The joint committee shall review and ensure that any proceeds resulting from the successful transfer be applied to the system of provision of services for long-term care and home and community based services.

(b) The joint committee shall consist of nine members as follows: (1) One member of the house of representatives appointed by the speaker of the house of representatives; (2) one member of the house of representatives appointed by the minority leader of the house of representatives; (3) one member of the senate appointed by the president of the senate; (4) one member of the senate appointed by the minority leader of the senate; (5) one member of the house of representatives appointed by the chairperson of the house committee on appropriations; (6) one member of the senate appointed by the chairperson of the senate committee on ways and means; (7) one member of the house of representatives appointed by the ranking minority member of the house committee on appropriations; (8) one member of the senate appointed by the ranking minority member of the senate committee on ways and means; and (9) one member of the house of representatives appointed by the majority leader of the house of representatives.

(c) Members shall be appointed for terms coinciding with the legislative terms for which such members are elected or appointed. All members appointed to fill vacancies in the membership of the joint committee and all members appointed to succeed members appointed to membership on the joint committee shall be appointed in the manner provided for the original appointment of the member succeeded. The first meeting of the joint committee shall be held before August 1, 2008.

(d) The members originally appointed as members of the joint committee shall meet upon the call of the member appointed by the speaker of the house of representatives, who shall be the first chairperson, within 30 days of the effective date of this act. The vice-chairperson of the joint committee shall be appointed by the president of the senate.

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Chairperson and vice-chairperson shall alternate annually between the members appointed by the speaker of the house of representatives and the president of the senate. The ranking minority member shall be from the same chamber as the chairperson. The joint committee shall meet at least four times each year at the call of the chairperson of the joint committee. Five members of the joint committee shall constitute a quorum.

(e) At the beginning of each regular session of the legislature, the committee shall submit to the president of the senate and the speaker of the house of representatives a written report on numbers of individuals transferred from the state or private institutions to the home and community based services including the average daily census in the state institutions and long-term care facilities, savings resulting from the transfer certified by the secretary of social and rehabilitation services and the secretary of aging in a quarterly report filed in accordance with K.S.A. 2008 Supp. 39-7,161 and 39-7,162, and amendments thereto, and the current balance in the home and community based services savings fund of the department of social and rehabilitation services and the department on aging.

(f) Members of the committee shall be paid compensation, travel expenses and subsistence expenses or allowance as provided in K.S.A. 75-3212, and amendments thereto, for attendance at any meeting of the joint committee or any subcommittee meeting authorized by the committee.

**History:** L. 2008, ch. 168, § 2; July 1.

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## 39-7,161

### Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE

### Article 7.--SOCIAL WELFARE

**39-7,161. Home and community based services savings fund administered by secretary of SRS; certification, transfer and expenditure.** (a) (1) There is hereby established the home and community based services savings fund in the state treasury which shall be administered by the secretary of social and rehabilitation services. All savings resulting from transferring individuals from the state or private institutions to home and community based services shall be deposited in this fund. All expenditures from the home and community based services savings fund shall be in accordance with the provisions of appropriation acts upon vouchers approved by the secretary of social and rehabilitation services or the secretary's designee.

(2) Whenever an individual, who is residing in an institution, transfers to home and community based services, the secretary of social and rehabilitation services shall determine the savings attributable to such transfer and shall certify the amount or amounts of such savings to the director of accounts and reports. Upon receipt of each such certification, the director of accounts and reports shall transfer the amount or amounts specified in such certification from the funds and accounts specified to the home and community based services savings fund of the department of social and rehabilitation services in accordance with such certification. The secretary of social and rehabilitation services shall transmit a copy of each such certification to the director of the budget and to the director of legislative research.

(b) The secretary shall certify to the joint committee on home and community based services oversight at the beginning of each calendar quarter the amount of savings resulting from transferring individuals from the state or private institutions to home and community based services that have been transferred during the preceding calendar quarter to the home and community based services savings fund from each state or private institution during the preceding quarter.

**History:** L. 2008, ch. 168, § 3; July 1.

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## 39-7,162

### Chapter 39.--MENTALLY ILL, INCAPACITATED AND DEPENDENT PERSONS; SOCIAL WELFARE

### Article 7.--SOCIAL WELFARE

**39-7,162. Home and community based services savings fund administered by secretary of aging; certification, transfer and expenditures.** (a) (1) There is hereby established the home and community based services savings fund in the state treasury which shall be administered by the secretary of aging. All savings resulting from transferring individuals from the institutions to home and community based services shall be deposited in this fund. All expenditures from the home and community based services savings fund shall be in accordance with the provisions of appropriation acts upon vouchers approved by the secretary of aging or the secretary's designee.

(2) Whenever an individual, who is residing in an institution, transfers to home and community based services, the secretary of aging shall determine the savings attributable to such transfer and shall certify the amount or amounts of such savings to the director of accounts and reports. Upon receipt of each such certification, the director of accounts and reports shall transfer the amount or amounts specified in such certification from the funds and accounts specified to the home and community based services savings fund of the department on aging in accordance with such certification. The secretary of aging shall transmit a copy of each such certification to the director of the budget and to the director of legislative research.

(b) The secretary shall certify to the joint committee on home and community based services oversight at the beginning of each calendar quarter the amount of savings resulting from transferring individuals from institutions to home and community based services that have been transferred during the preceding calendar quarter to the home and community based services savings fund from each institution during the preceding quarter.

**History:** L. 2008, ch. 168, § 4; July 1.

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# Report of the Joint Committee on Home and Community Based Services Oversight to the 2009 Kansas Legislature

**CHAIRPERSON:** Representative Bob Bethell

**VICE-CHAIRPERSON:** Senator Pat Apple

**OTHER MEMBERS:** Senators David Haley, Laura Kelly, and Dwayne Umbarger; and Representatives Jerry Henry, Brenda Landwehr, Melody McCray-Miller, and Sharon Schwartz

## STUDY TOPIC

- **Long-Term Care System in Kansas.** Review the current system of long-term care in Kansas, including the potential for global funding of long-term care by which no one is denied service in the manner they choose. Study other states that have implemented this method of services, specifically Washington, Vermont, and New Jersey. Also review the implementation of a global home and community based services waiver that provides services regardless of determining factor for the individual to be eligible for service.

*December 2008*

Joint Home and Community Based Services
Date: 10/14/09
Attachment: 3

# Joint Committee on Home and Community Based Services Oversight

## REPORT

### CONCLUSIONS AND RECOMMENDATIONS

Based on the testimony heard and the Committee deliberations, the Home and Community Based Services Oversight Committee reached the following conclusions.

- Individuals receiving waiver services should have the opportunity to be gainfully employed. Therefore, the Committee will further consider the availability of vocational training for these individuals during the upcoming year. In particular, the Committee will examine the availability and level of vocational training in school districts for individuals receiving waiver services. It also will examine the availability of good data to determine the effectiveness of the current training programs and any legal obstacles to collecting that data.

- The Committee will continue to pursue ways for individuals seeking social and health services to have the ability to access services information through a single portal regardless of where they live in the state. In particular, the Committee will look for ways to strengthen the current 2-1-1 referral system in place in the state and to expand the locations where the AAA Resource Directory is made available.

- The Committee will continue to study the feasibility of expanding waiver services to children ages three and four who have special needs. In particular, the Committee will examine whether a gap in services exists for these children. The Committee will review the number of three and four-year olds currently enrolled in therapeutic preschools or preschools that offer social services and the availability of preschools who accept children with special needs.

- The Committee will continue to monitor the number of individuals on waiting lists for waiver services, autism services and infant-toddler services.

- For all waiver services, the Committee will continue to monitor the high turnover rate of direct care staff. In particular, the Committee will review available options to help retain quality direct care staff including increased compensation, enhanced benefits, and better working conditions.

- For all waiver services, the Committee will review the significant advancements in health care technology that allow more services to be provided to individuals with special needs while utilizing less staff and enhancing the health, safety and security of those individuals. The review will include the use of technological advancements in rural areas. The Committee also recommends that the use of health care technology in the care of individuals with special needs be a topic of consideration in the appropriate committees and subcommittees during the 2009 Legislative Session.

- The Committee will continue to monitor the Money-Follows-the-Person Program. As set out in the charge for the Oversight Committee, the Committee will monitor the movement of individuals and the transfer of funding into home and community based services.
- In future committee meetings and where applicable, the Committee may consider reviewing the availability and adequacy of services provided to the parents of children who are in the process of being reintegrated into the family.
- The Committee and the appropriate state agencies will contact the Kansas Congressional Delegation concerning the need for adequate reimbursement rates from the federal government to better ensure the availability of services, particularly in rural areas. The Committee also will review the state's funding policies to ensure that the rural areas are being adequately served.
- The Committee will review the reimbursement rates for Home and Community Based Services to determine if the reimbursement rates allow providers to earn a return sufficient to continue providing services in the community.
- The Committee will begin the process of developing a comprehensive, integrated approach to the provision of health care in rural areas within the broader context of rural development. In particular, the Committee will take the dialogue concerning rural health beyond the Committee and begin to work with other entities in state government, such as the newly created Division of Rural Development within the Department of Commerce; with local communities; and with stakeholders. The goal of the Committee's efforts will be to make as many services available in rural communities as economically feasible.

***Proposed Legislation:*** None.

## BACKGROUND

The Joint Committee on Home and Community Based Services Oversight operates pursuant to KSA 39-7,159, *et seq.* The Oversight Committee was created by the 2008 Legislature in House Sub. for Senate Bill 365. Senate Bill 365 sets forth the goal that long-term care services, including home and community based services, are to be provided through a comprehensive and coordinated system throughout the state. The system, in part, is to emphasize a delivery concept of self-direction, individual choice, services in home and community settings, and privacy.

The Oversight Committee is composed of nine members, five from the House of Representatives and four from the Senate. Members are appointed for terms that coincide with their elected or appointed legislative terms. The Committee is to meet at least four times each year at the call of the chairperson. In its oversight role, the Committee is to oversee the savings resulting from the transfer of individuals from state or private institutions to home and community based services and to ensure that any proceeds resulting from the successful transfer be applied to the system for the provision of services for long-term care and home and community based services. Additionally, the Committee is to review and study other components of the state's long-term care system.

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As required in Senate Bill 365, at the beginning of each regular session, the Committee is to submit a written report to the President of the Senate and the Speaker of the House of Representatives which includes: the number of individuals transferred from state or private institutions to home and community based services; the average daily census in state institutions and long-term care facilities; the savings resulting from the transfer of individuals to home and community based services as certified by the Secretary of Social and Rehabilitation Services and the Secretary of Aging; and the current balance in the Home and Community Based Services Savings Fund. Additionally, the Kansas Department on Aging (KDOA) and the Kansas Department of Social and Rehabilitation Services (SRS), in consultation with the Kansas Health Policy Authority, are to submit an annual report on the long-term care system to the Governor and the Legislature during the first week of each regular session.

## COMMITTEE ACTIVITIES

The Oversight Committee held four one-day meetings in the 2008 Interim. The Committee's work focused on the following areas:

- Reviewing the funding targets recommended in the Legislative Budget Committee Report to the 2007 Legislature with the intent that the funding targets be used as guidelines for future funding, planning and policy making;
- Reviewing the number of individuals who, since July 1, 2008, have been transferred from state or private institutions and long-term care facilities to home and community based services and the associated cost savings and other outcomes of the Money-Follows-the-Person Program;
- Providing oversight of the savings resulting from the transfer of individuals from state or private institutions to home and community based services to ensure that proceeds resulting from successful transfers be applied to the system for the provision of services for long-term care and home and community based services;
- Studying and determining the effectiveness of the transfer program and the impact on state institutions and long-term care facilities;
- Determining whether adequate progress is being made to transfer individuals from institutions and from waiver waiting lists to home and community based services; and
- Considering whether sufficient funding is provided for the enhancement of wages and benefits and for the training of direct, individual care workers.

Additionally, the Legislative Coordinating Council (LCC) requested that the Committee review the current system of long-term care in Kansas, including the potential use of global funding for long-term care. The LCC also requested the Committee to review the implementation of a global home and community based services waiver that would allow long-term care services to be provided regardless of the specific waiver factors that make individuals eligible for long-term care services.

Within the framework of the above directives, the Committee received testimony from state agencies, providers, associations, and other stakeholders in the areas discussed below.

### Review of the Report of the Legislative Budget Committee to the 2007 Kansas Legislature

The Committee received an overview of the funding recommendations made in the Legislative Budget Committee Report to the 2007 Legislature. The funding recommendations

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were made to establish a phased-in effort to accomplish the linked programmatic goals of expanding community capacity and eliminating the waiting list for Home and Community Based Services for persons with Developmental Disabilities (HCBS/DD) waiver. The funding recommendations included:

- Adding $15 million from the State General Fund in FY 2008 and $10 million State General Fund in FY 2009 and FY 2010 to expand community capacity through rate adjustments which would more closely reflect parity between community wages and state institutional wages.
- Adding $10 million from the State General Fund in both FY 2008 and FY 2009 and $15 million in FY 2010 to eliminate the waiting lists for developmental disability waiver services.

### Status of Long-Term Care Services in Kansas

The Committee received testimony on the status of long-term care services in Kansas. The testimony included information on long-term care trends in the state and the home and community based service waivers currently being implemented.

Kathy Greenlee, Secretary of Aging, provided an overview of the American Association of Retired Persons (AARP) report *A Balancing Act: State Long-Term Care Reform* which examined the extent to which states have balanced the delivery of Medicaid-funded long-term care services and supports between institutions and home and community based services. Secretary Greenlee stated that, of its Medicaid long-term care dollars for older persons and adults with physical disabilities, Kansas allocates a greater percentage (34 percent) to home and community based services as compared to the U.S. average (25 percent). In 2006, Kansas ranked tenth in the country in the percent of Medicaid dollars spent on home and community based services. She also stated that Kansas should look to Oregon, New Mexico, Washington, and Arkansas as peer states to emulate.

Dr. Rosemary Chapin, who directs the Office of Aging and Long Term Care (OALTC) at the University of Kansas School of Social Welfare, discussed research that OALTC has conducted in collaboration with the Kansas Department on Aging, the Kansas Department of Social and Rehabilitation Services, the Area Agencies on Aging (AAAs), the Kansas University School of Pharmacy, and the Kansas University School of Medicine. Dr. Chapin stated that Kansas has made great strides in rebalancing the long-term care system and using tax dollars more effectively. However, Kansas is still institutionalizing older citizens at a higher rate than the national average which is costing the state more money than necessary to meet the needs of many Kansans. Conclusions drawn from three studies showed that Medicaid Home and Community Based Services are cost effective and typically are less costly for the state than nursing home services. Also, older adults appear to stabilize after a period of receiving HCBS services and are able to live in the community without state funded services, often with informal care provided by family and friends.

Dr. Chapin also discussed the trends expected to affect long-term care between now and 2020. OALTC used a 2002 AARP report on trends in long-term care as a framework to explore long-term care trends in Kansas. She stated that the older adult population in Kansas will incrementally increase in contrast to the national trend. Also, the older adult population in Kansas is becoming more diverse and disparities in disability and poverty among racial and ethnic groups exist that could impact their demand for long-term care. Additionally, Dr. Chapin discussed mental health services for older adults and stated that, currently, older adults with mental health needs are underserved.

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A representative from AARP Kansas provided written testimony about the state of long-term care in Kansas noting that the ranking for Kansas in dollars spent for home and community based services changes when the statistics for older Kansans are reviewed. Compared to the U.S. as a whole, Kansas had a significantly higher rate of persons age 65 and over living in nursing homes. In 2007, for every 100 persons over age 65 in Kansas, 5.15 were nursing home residents as compared to the national number of 3.6 nursing home residents. Kansas is ranked sixth highest in the nation.

Testimony was provided by the Executive Director of the Kansas Area Agencies on Aging Association (K4A), which represents the 11 AAAs in Kansas. The Executive Director stated that the Area Agency on Aging system is funded by federal, state, and local resources; is administered locally; and the service delivery decisions are made at the community level - often in the homes of seniors who need services that make independent living a viable option. The Committee was provided with copies of the 2008 Quality Review Report for the Home and Community Based Services for the Frail Elderly (HCBS/FE) Waiver prepared by the Department on Aging which showed that the overall statewide compliance score for the AAAs for the first quarter of FY 2008 was 97 percent.

An individual representing the Northeast Kansas AAA, stated that the AAAs are federally mandated to advocate for seniors and are the single point of entry for seniors needing services. It was stated that the HCBS/FE waiver is the most cost efficient of the major waivers, had the most clients, and realized an annual savings to taxpayers of more than $115 million.

Representatives of SRS and KDOA updated the Committee on existing long-term services that included information on the waiting lists for the HCBS waivers, the status of the Money-Follows-the-Person program (MFP), adult day care services, and budget issues.

The Committee received an overview of the Program of All-Inclusive Care for the Elderly (PACE) program from a representative of the Department on Aging who explained that PACE is a capitated benefit authorized by the federal government in 1997. It is a comprehensive service delivery system that integrates Medicare and Medicaid financing and allows most participants to continue to live at home while receiving services. Representatives of the two PACE providers in the state, Via Christi HOPE located in Wichita and Midland Care PACE located in Topeka, provided testimony about their programs. The PACE representatives noted that PACE is an alternative to traditional long-term care placement; providers are at full risk for all costs approved by the PACE Interdisciplinary Team Program; the state can realize savings from the co-payments made by program enrollees whose incomes are above $747 per month; and with capitated payments from Medicaid, PACE enhances the state's ability to predict costs for the long-term care population as well as fulfilling an individual's goal of remaining in the home.

## Stakeholder Concerns and Recommendations for Changes to the Long-Term Care System

The Committee requested input from stakeholders on suggested changes to the state's long-term care system. The stakeholders providing testimony included representatives of state agencies, associations, and service providers.

**Agency Recommendations.** Representatives of the Department of Social and Rehabilitation Services highlighted the need for advocacy, whether through the role of the State Long-Term Care Ombudsman or self-advocacy; the need to ensure that the HCBS waivers are of high quality, offering care that does not focus on paperwork; the need to ensure that patients' expectations are being met; and the need to ensure that the state is getting what it pays for while patients are getting what they need. The Real Choice-Systems

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Transformation Planning grant was discussed as allowing Kansas to conduct an independent, unbiased review of the systems that are in place to assess the long-term care needs of individuals. It also will assess the operational structure of the long-term care system including cost determination of the services provided.

A representative of the Department on Aging stated that the Department continues to support self-direction, individual choice, home and community-based services, and privacy. The Department continues to conduct quality assurance surveys which have shown a high level of satisfaction with the services provided. Additionally, the Department, along with SRS and the Kansas Health Policy Authority, work closely with stakeholders and advocates in designing and implementing long-term care services.

A representative of the Kansas Health Policy Authority reiterated the Authority's role to ensure compliance with the state and federal laws and rules governing the state's Medicaid programs. The representative also noted the importance of continued collaboration among the state and federal agencies responsible for the development of Medicaid policy.

The State Long-Term Care Ombudsman stated that, at present, ombudsman services do not include private homes or other non-licensed settings. The representative recommended that the Oversight Committee begin a dialogue to explore advocacy options within the Money-Follows-the-Person program. Also, he recommended that two more ombudsmen be added to bring Kansas in line with the Institute of Medicine's recommendation of one ombudsman for every 2,000 residents.

The executive director of the Area Agencies on Aging Association, cautioned the Committee against developing health care institutions in individuals' homes. Additionally, a representative from the Northeast Kansas AAA, opposed moving to a single waiver system (global home and community based waiver). He stated that waiver philosophies are different, waiver goals for participants are different, waiver services are different for different targeted populations, and individual needs are different. Concerning the Money Follows the Person Program (MFP), he stated that the AAAs are committed to making the MFP Program work. However, concerns were expressed about the definition of a "home"; that payment for services provided by the AAAs would be delayed until the person actually leaves the nursing facility; that no payment would be received if the person does not leave the nursing facility; that only 48 hours of "transition services" are allowed; that some areas of the state lack affordable housing; and that some Plans of Care will cost more than the care provided in a nursing facility.

**Association Recommendations.** Testimony from a representative of the Kansas Health Care Association noted that the barriers to community placement should be removed; adequate funding must be provided for the spectrum of facility and HCBS services; quality assurance systems must be built into all services and support programs; and consumer protections must be enforced through appropriate government regulation; and accountability measures need to be put in place for taxpayer funds when hiring non-traditional caregivers. Additionally, the representative recommended the Committee review Tennessee's Long Term Care Community Choices Act of 2008.

A representative of the Kansas Advocates for Better Care mentioned the need for an independent, objective, authority able to intervene to address safety, health, and welfare issues on behalf of adults who will receive home and community-based services as they make the transition from nursing homes to community settings with services. The representative also noted that the current State Long-Term Care Ombudsman program does not have the authority, staff, or funding to provide adequate oversight.

A representative of the Kansas Association of Homes and Services for the Aging reiterated its commitment to promote diversification; to participate in development of quality indicators and core competencies for community-based service providers; and to work with policymakers and state agencies in identifying policies that support transformation of nursing homes into aging service centers.

Testimony from a representative of the Kansas Association of Centers for Independent Living discussed the need to continue to support self-direction in Kansas; maintain and expand funding in all HCBS programs; establish a solid diversion program which includes expedited service delivery for all HCBS waiver programs; and increase direct care worker rates.

A representative of the Kansas Home Care Association discussed the need for reimbursing at a rate that allows agencies to recruit competitively and retain staff by offering a sufficient living wage. In addition, the representative noted the importance of supporting the expansion of technological advances such as telecare.

A representative of the Disability Rights Center of Kansas discussed the need to eliminate all waiting lists; to expand capacity over a three year period; to right-size institutional beds; and to add less expensive more desired HCBS services.

A representative from InterHab noted the need to increase reimbursement rates to allow providers to offer wages for direct care staff that are comparable with what the state pays its own direct care workers and to eliminate the two waiting lists by implementing the Legislative Budget Committee recommendations.

**Provider Recommendations.** The Committee received testimony from representatives of HCBS providers; one representative shared his sense of urgency that the waiting list currently in place for persons with developmental disabilities be eliminated within three years as was suggested by the Legislative Budget Committee Report to the 2007 Legislature. He expressed urgency that adequate resources be made available for the expansion of community services as also recommended by the Legislative Budget Committee. Concerns were expressed that funding for the federally mandated Infant-Toddler Services (*tiny-k*) Program has not kept pace with the increase of children coming into the Program and urged that the Program be fully funded. By federal law, *tiny-k* Programs cannot turn a child away. Additionally, the representative requested that the Committee examine the state policy that arbitrarily sets an age limit of five years or older to be eligible to participate in the HCBS Developmental Disability Waiver (HCBS/DD).

The President of Developmental Services of Northwest Kansas (DSNWK), expressed concern about the funding shortfalls for community services for the developmentally disabled and shared with the Committee the service closures that DSNWK has begun to implement in response to the funding shortfalls. The representative also urged the Committee to implement the recommendations made in the Legislative Budget Committee Report to the 2007 Legislature a top priority.

The President of the Kansas Elks Training Center for the Handicapped (KETCH), provided testimony to demonstrate that the best assistance for persons with developmental disabilities is to help them become employed in competitive jobs. He stated that employment leads to increased levels of independence, a better quality of life, and can result in cost savings for services the developmentally disabled receive. He stated that the maximum Social Security Income benefit is $637 per month or $7,644 per year which is below the federal poverty level of $10,400. He also provided the results of a 2006 Gallup poll, a DePaul University study commissioned by the Chicago Chamber of Commerce, and two national studies by the Harris Poll supporting

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the positive benefits of hiring persons with developmental disabilities. He also stated that the largest barrier continues to be the attitude of employers that persons with disabilities cannot work. Other barriers include the initial training costs, fear of loss of other benefits, and instability of funding for employment service providers. Additionally, the August 2008 Developmental Disability Service Report published by SRS indicated that of all persons with developmental disabilities receiving funding in Kansas for day services, only 19 percent are employed.

The Executive Director of InterHab stated that the underfunding of reimbursement rates has placed the progress made in the developmental disabilities programs in doubt and the system is in jeopardy. He cited the difference between the approximately $12 average hourly wage of state institutional workers as compared to the approximately $9 average hourly wage of community workers as the most dramatic instance of rate inadequacy. Additionally, programs offering employment and vocational training for persons with disabilities are in danger of disappearing from the community network. He recommended that the Oversight Committee support the funding recommendations in the Legislative Budget Committee Report to the 2007 Legislature.

In written testimony, representatives of the Coordinating Council on Early Childhood Developmental Services responded to the LCC request concerning a global home and community based services waiver. The Council encouraged the Committee to revisit the current policy provision that limits most HCBS waivers to persons over the age of five years. Additionally, the Council urged consideration for adequate funding to meet the needs for all individuals on waiting lists for services. The Council also requested that serious consideration be given to make the waiver process as user-friendly as possible in that Kansas families still struggle to navigate a very complicated system.

## Other Long-Term Care Issues

**Funding for Direct Care Staff.** The Oversight Committee received an update concerning the issue of adequate funding for direct care workers. An auditor from Legislative Post Audit, provided a review of the 2008 Performance Audit, *Disability Waiver Programs: Reviewing the Use of Appropriations Intended to Upgrade the Wages of Certain Caregivers*. The Post Audit noted that the Legislature appropriated $27.5 million in FY 2007, and $27.2 million in FY 2008 for the reduction of the waiting lists for the Developmental Disabilities and Physical Disabilities waivers and to increase wages for direct caregivers. The increase for caregiver wages was specified by the Legislature for FY 2007 but not specified for FY 2008. In a 2007 memorandum from the Department of Social and Rehabilitation Services to service providers, there was no mention of the Legislature's intention to provide a wage increase for direct care workers. Post Audit sampled five developmentally disabled service providers, and determined that the direct caregivers average hourly wages were increased by approximately three to 11 percent in FY 2007, and two to 10 percent in FY 2008. Additionally noted was that not every caregiver received an increase due to other various factors. Post Audit sampled five physically disabled service providers, and determined that only two of the five providers increased direct caregivers average hourly wages by three to 10 percent in FY 2008. The other three providers reported using the additional funding to increase administrative staff positions, pay for overhead costs, and pay for existing debt. Legislative Post Audit recommended that to "help ensure that any funding appropriated by the Legislature for specific purposes is used as intended, the Department of Social and Rehabilitation Services should clearly and formally communicate that intent to service providers."

**Single Portal for Information on Services.** The Committee discussed the need for individuals seeking social and health services to have the

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ability to access information about services through a single portal regardless of where they live in the state. The Committee commented that the state has made a substantial dollar investment in providing social and health services and that it is important that individuals have access to all available services to better ensure that they receive the right level of care which, in turn, can reduce the cost of services. The Committee asked questions about existing outreach efforts and discussed additional efforts to communicate the availability of services. In addition to the resource directories made available by the AAAs, suggestions for expanded or additional outreach included the use of local newspapers, churches and the 2-1-1 Information and Referral Search service. A representative of United Way of the Plains located in Wichita, which is the parent agency for the 2-1-1 service in Kansas, stated that she would suggest that United Way do an article about the service in rural newspapers. She also mentioned that the strength of the 2-1-1 system relies on the input of the various agencies.

**Vocational Training in Schools.** The Committee received testimony from a representative of the Kansas State Department of Education who stated that issues for students with special needs are driven by an Individualized Education Plan (IEP) for each student. The IEP is to ensure that each student has access to the general curriculum in the least restrictive environment. The Committee also received testimony from representatives of the Girard and Olathe school districts who described their respective vocational training programs. The Committee acknowledged the value of the vocational training being provided but expressed concern about the follow up provided to students entering postsecondary education or transitioning into the labor market.

**Targeted Case Management.** The Committee reviewed the effects of the implementation of the new targeted case management (TCM) rules. The Committee discussion centered around the concerns that service providers are no longer allowed to submit for reimbursement the time used for travel to visit clients and the potential difficulties faced by the Area Agencies on Aging because the Department on Aging may no longer limit targeted case management services for the HCBS/FE waiver and must allow any qualified provider to perform the services. The topic was assigned to the Legislative Budget Committee and the Committee's complete discussion can be found in the Legislative Budget Committee Report to the 2009 Legislature.

**Global Funding; Global HCBS Waiver.** The Committee was provided an overview of the topic of global funding (global budgeting) and it was noted that there is no standard definition of global budgeting which created difficulties in reporting the states that have implemented it. The Committee specifically reviewed the policies implemented by Vermont and Washington. The executive director for the Statewide Independent Living Council of Kansas (SILCK) provided another perspective on global funding. She stated that global funding should not be thought of as all programs being in a single state agency, nor a single HCBS strategy for each consumer in the program, it needs to be thought of in terms of uniform and interchangeable funding between the agencies, it should hold each HCBS program accountable for the well being of each person, it should open the door for SRS and KDOA to make a global report as to the amount of money being spent for all long term care services, and it should allow the comparison of activities of various programs to see what lessons can be learned between the programs.

## Annual Report to the 2009 Legislature

As discussed above, the Oversight Committee is charged by statute to submit an annual written report to the President of the Senate and the Speaker of the House of Representatives at the start of each regular legislative session. The Committee's Annual Report is to be based on information submitted quarterly to the Committee by the Secretary of Social and

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Rehabilitation Services and the Secretary of Aging. Because the authorizing legislation creating a comprehensive and coordinated statewide system for long-term care services was effective July 1, 2008, implementation of the data reporting requirements is preliminary, with only one quarter of information available to the Committee. Therefore, the initial Annual Report is included as this section of the Interim Report.

In preparation for the Annual Report, the Committee received testimony from representatives of the Department of Social and Rehabilitation Services, the Department on Aging, and the Kansas Legislative Research Department (KLRD). In the initial Quarterly Report submitted to the Committee, representatives of SRS and KDOA provided examples of the data being collected to meet the statutory reporting requirements.

- Number of individuals transferred from state or private institutions to home and community based services -

For each transferred person, the report included the waiver program the person was participating in; whether that person was eligible for the federal Money-Follows-the-Person Program or the state Money-Follows-the-Person Program; and the pre-institutional setting for the person. No transfers were made in the initial reporting quarter but the agencies have begun the process of identifying persons who may be eligible to transfer to a community setting.

- Savings resulting from the transfer of individuals to home and community based services as certified by the Secretary of Social and Rehabilitation Services and the Secretary of Aging -

For each transferred person, the Quarterly Report provided the previous institutional setting; the annualized cost for that institution; the date of admission and discharge from the institution; the community waiver services being received; the federal and state costs for the annual plan of care; the Money-Follows-the-Person Program supplements and, where appropriate, the ICF/MR bed closure cost; the quarterly projected costs and savings; and the projected year one and out year costs and savings. The costs and savings information included in the initial Quarterly Report were for illustrative purposes only.

- Current balance in the Home and Community Based Services Savings Funds -

There were no transfers made to the Home and Community Based Services Savings Funds administered by the Department of Social and Rehabilitation Services and the Department on Aging in the initial reporting quarter.

- Average daily census in state institutions and long-term care facilities -

The average daily census for the first reporting quarter from July 1, 2008 to September 30, 2008 showed the following changes:

*Kansas Neurological Institute* - the average daily census changed from 157 to 158, with one discharge to the community.

*Parsons State Hospital* - the average daily census changed from 188 to 182, with eight discharges to the community.

*Private ICFs/MR* - the average daily census changed from 278 to 224, with 56 discharges to the community.

*Nursing Facilities* - the average daily census changed from 17,939 to 17,793, with 2,146 discharges to the community.

It should be noted that the discharges to the community include, but are not solely, transfers to home and community based services.

As background information, KLRD staff also provided a ten-year average daily

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census for the state mental hospitals and the state developmental disabilities hospitals. In discussion with the Committee, representatives of SRS and KDOA explained the complexities of the reporting requirements, that savings can only be spent on one-time startup costs such as modification of housing, and that the initial move from an institution to a community can cost the state more than was being provided for institutional care.

## CONCLUSIONS AND RECOMMENDATIONS

Based on the testimony heard and the Committee deliberations, the Home and Community Based Services Oversight Committee reached the following conclusions.

- Individuals receiving waiver services should have the opportunity to be gainfully employed. Therefore, the Committee will further consider the availability of vocational training for these individuals during the upcoming year. In particular, the Committee will examine the availability and level of vocational training in school districts for individuals receiving waiver services. It also will examine the availability of good data to determine the effectiveness of the current training programs and any legal obstacles to collecting that data.
- The Committee will continue to pursue ways for individuals seeking social and health services to have the ability to access services information through a single portal regardless of where they live in the state. In particular, the Committee will look for ways to strengthen the current 2-1-1 referral system in place in the state and to expand the locations where the AAA Resource Directory is made available.
- The Committee will continue to study the feasibility of expanding waiver services to children ages three and four who have special needs. In particular, the Committee will examine whether a gap in services exists for these children. The Committee will review the number of three and four-year olds currently enrolled in therapeutic preschools or preschools that offer social services and the availability of preschools who accept children with special needs.
- The Committee will continue to monitor the number of individuals on waiting lists for waiver services, autism services and infant-toddler services.
- For all waiver services, the Committee will continue to monitor the high turnover rate of direct care staff. In particular, the Committee will review available options to help retain quality direct care staff including increased compensation, enhanced benefits, and better working conditions.
- For all waiver services, the Committee will review the significant advancements in health care technology that allow more services to be provided to individuals with special needs while utilizing less staff and enhancing the health, safety and security of those individuals. The review will include the use of technological advancements in rural areas. The Committee also recommends that the use of health care technology in the care of individuals with special needs be a topic of consideration in the appropriate committees and subcommittees during the 2009 Legislative Session.
- The Committee will continue to monitor the Money-Follows-the-Person Program. As set out in the charge for the Oversight Committee, the Committee will monitor the movement of individuals and the transfer of funding into home and community based services.

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- In future committee meetings and where applicable, the Committee may consider reviewing the availability and adequacy of services provided to the parents of children who are in the process of being reintegrated into the family.

- The Committee and the appropriate state agencies will contact the Kansas Congressional Delegation concerning the need for adequate reimbursement rates from the federal government to better ensure the availability of services, particularly in rural areas. The Committee also will review the state's funding policies to ensure that the rural areas are being adequately served.

- The Committee will review the reimbursement rates for Home and Community Based Services to determine if the reimbursement rates allow providers to earn a return sufficient to continue providing services in the community.

- The Committee will begin the process of developing a comprehensive, integrated approach to the provision of health care in rural areas within the broader context of rural development. In particular, the Committee will take the dialogue concerning rural health beyond the Committee and begin to work with other entities in state government, such as the newly created Division of Rural Development within the Department of Commerce; with local communities; and with stakeholders. The goal of the Committee's efforts will be to make as many services available in rural communities as economically feasible.

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Joint Committee on Home and Community
Based Services Oversight
October 14, 2009
Attachment 4

## Home and Community Based Service Waivers (HCBS) from all funding sources FY 2000 to FY 2011 Agency Request

| | FY 2000 | FY 2001 | FY 2002 | FY 2003 | FY 2004 | FY 2005 | FY 2006 | FY 2007 | FY 2008 | FY 2009 | FY 2010 Approved | FY 2010 Agency Revised Estimate* | FY 2011 Agency Base Request | FY 2011 Agency Enhancements | FY 2011 Agency Total Request |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ***Department on Aging*** | | | | | | | | | | | | | | | |
| HCBS/FE | $ 44,748,114 | $ 49,527,953 | $ 58,223,782 | $ 53,529,370 | $ 45,069,948 | $ 54,125,403 | $ 55,706,959 | $ 63,264,442 | $ 68,765,887 | $ 72,096,548 | $ 70,584,341 | $ 71,561,929 | $ 70,657,621 | $ 5,605,679 | $ 76,263,300 |
| ***Deparment of Social and Rehabilitation Services*** | | | | | | | | | | | | | | | |
| HCBS/DD | 170,350,998 | 175,759,758 | 189,467,567 | 194,605,709 | 204,954,171 | 217,398,123 | 221,149,613 | 248,145,859 | 279,254,523 | 293,283,426 | 286,140,029 | 304,780,365 | 297,383,397 | 9,389,828 | 306,773,225 |
| HCBS/PD | 52,369,330 | 57,604,827 | 60,528,414 | 60,457,651 | 59,736,010 | 70,857,648 | 80,980,683 | 94,423,948 | 102,144,039 | 139,059,707 | 123,260,693 | 138,709,502 | 117,123,793 | 10,355,897 | 127,479,690 |
| HI/TBI | 4,847,074 | 3,607,662 | 3,883,033 | 4,593,058 | 5,455,886 | 5,703,934 | 3,400,107 | 8,277,479 | 6,844,597 | 10,882,090 | 8,065,901 | 11,056,584 | 8,065,901 | 2,990,683 | 11,056,584 |
| TA | 125,885 | 153,178 | 121,642 | 166,401 | 181,244 | 182,470 | 112,115 | 179,712 | 240,806 | 18,189,216 ** | 21,652,180 | 24,350,136 | 21,652,180 | 2,728,352 | 24,380,532 |
| Autism | [redacted] | [redacted] | [redacted] | [redacted] | [redacted] | [redacted] | [redacted] | [redacted] | 744,417 | 531,301 | 1,252,064 | 1,252,064 | 1,252,064 | | 1,252,064 |
| **TOTAL** | $ 272,441,401 | $ 286,653,378 | $ 312,224,438 | $ 313,352,189 | $ 315,397,259 | $ 348,267,578 | $ 361,349,477 | $ 414,291,440 | $ 457,994,269 | $ 534,042,288 | $ 510,955,208 | $ 551,710,580 | $ 516,134,956 | $ 31,070,439 | $ 547,205,395 |

Agency revised estimate includes internal agency shifts, including shifts from the state hospitals.

' In FY 2009, all expenditures for the Attendant Care for Independent Living Program were shifted to the Technology Assistance Waiver.

Staff Note: Prior to FY 2009 numbers also included Targeted Case Management Services

Joint Committee on Home
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Attachment 5

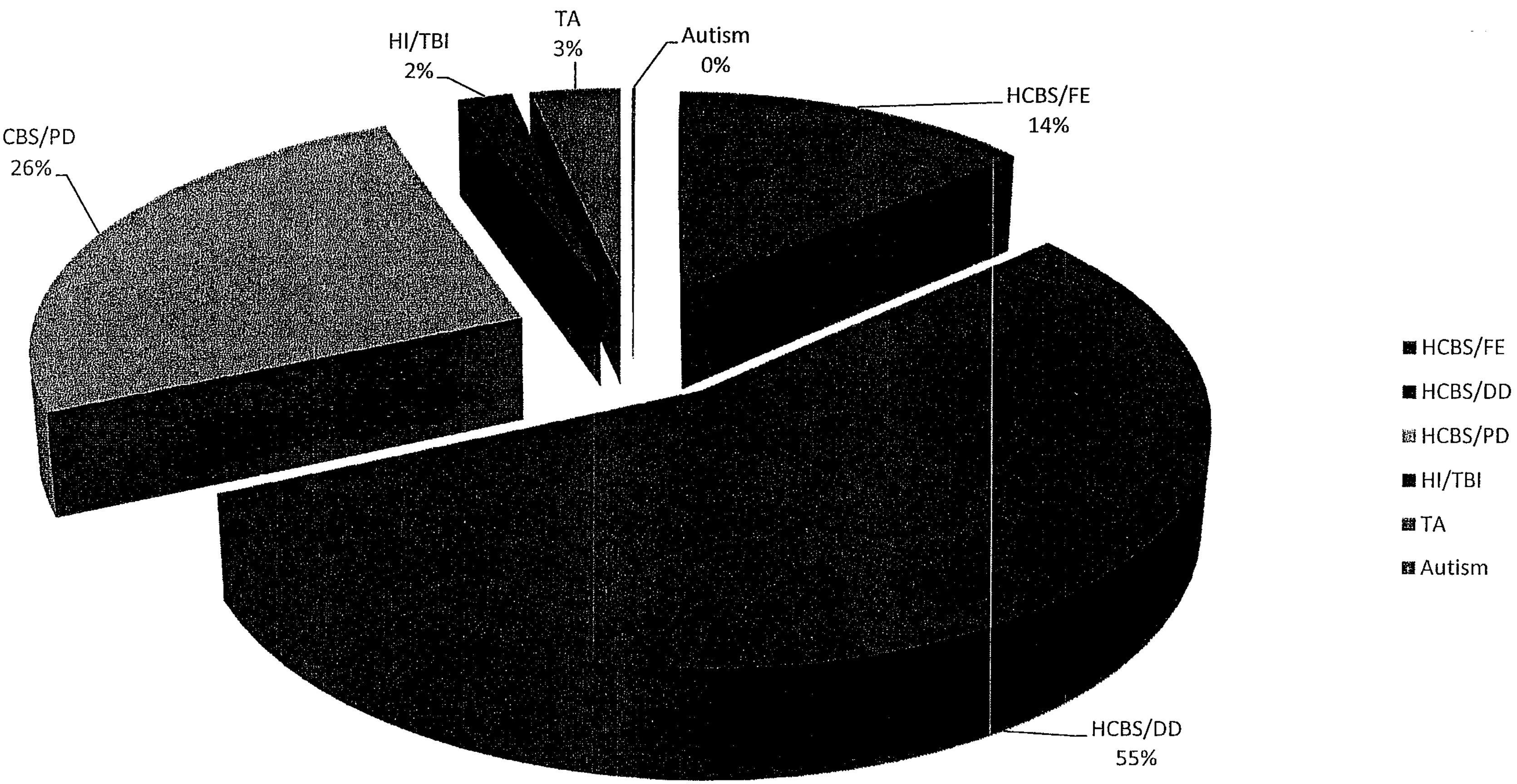
# Home and Community Based Service Waivers (HCBS) from the State General Fund
## FY 2008 to FY 2011 Agency Request

| | FY 2008 | FY 2009 | FY 2010 Approved | FY 2010 Agency Revised Estimate* | FY 2011 Agency Base Request | FY 2011 Agency Enhancements | FY 2011 Agency Total Request |
|---|---|---|---|---|---|---|---|
| ***Department on Aging*** | | | | | | | |
| HCBS/FE | $ 26,246,366 | $ 25,151,011 | $ 21,849,770 | $ 21,737,877 | $ 24,707,557 | $ 1,960,194 | $ 26,667,751 |
| ***Deparment of Social and Rehabilitation Services*** | | | | | | | |
| HCBS/DD | 109,519,509 | 97,967,491 | 88,732,023 | 86,542,290 | 99,656,087 | 3,283,435 | 102,939,522 |
| HCBS/PD | 44,229,044 | 48,121,139 | 38,223,141 | 42,146,882 | 40,955,848 | 3,621,250 | 44,577,098 |
| HI/TBI | 3,542,533 | 3,795,393 | 2,501,236 | 2,501,602 | 2,820,484 | 1,045,782 | 3,866,266 |
| TA | 48,919 | 6,056,066 | 6,714,341 | 6,579,015 | 7,571,334 | 954,050 | 8,525,384 |
| Autism | 6,526 | 176,132 | 388,265 | 380,440 | 437,822 | - | 437,822 |
| **TOTAL** | $ 183,592,897 | $ 181,267,232 | $ 158,408,776 | $ 159,888,106 | $ 176,149,132 | $ 10,864,711 | $ 187,013,843 |

Staff Note: The FMAP rate for Kansas Medicaid programs was increased beginnning October 2009 due to the federal American Recovery and Reinvestment Act of 2009 (ARRA). This increased the federal share and decreased the state portion for Medicaid expenditures.

Joint Committee on Home
and Community Based
Services Oversight
October 14, 2009
Attachment 6

# HCBS Waivers FY 2009 Expenditures from All Funding Sources

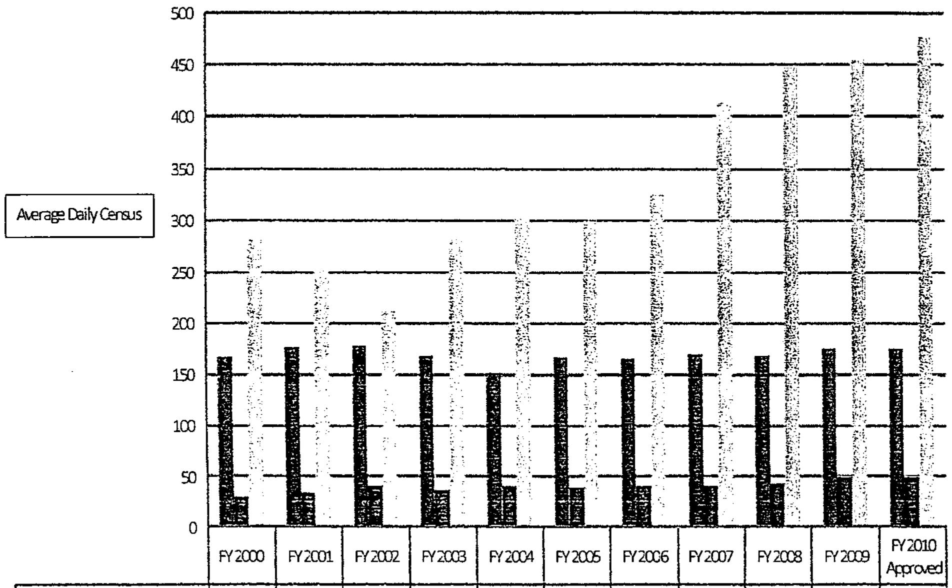


Joint Committee on Home
and Community Based
Services Oversight
October 14, 2009
Attachment 7

# 10 Year State Hospital Average Daily Census

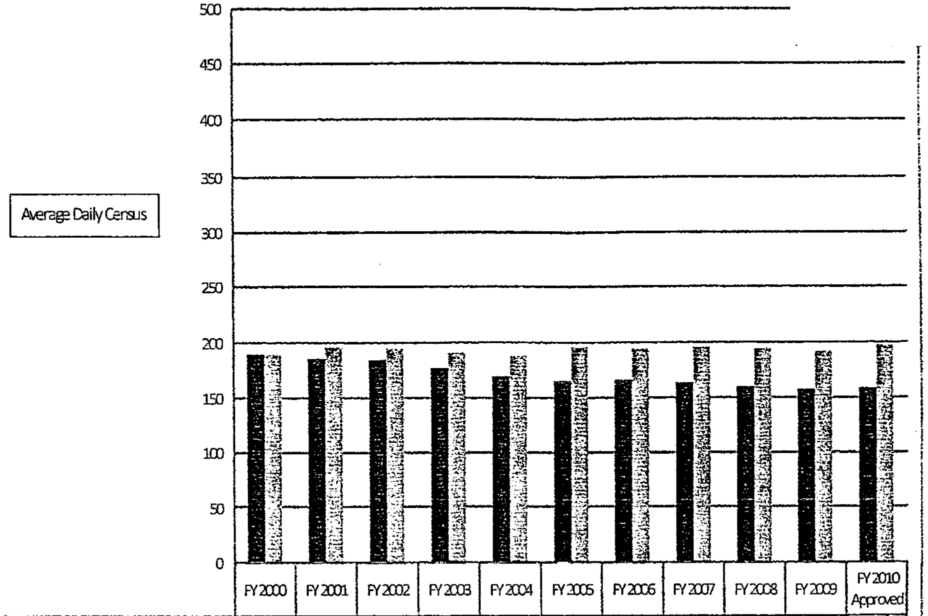
The Average Daily Census (ADC) represents the average number of patients in a hospital over a fiscal year.

## State Mental Health Hospitals



| | FY 2000 | FY 2001 | FY 2002 | FY 2003 | FY 2004 | FY 2005 | FY 2006 | FY 2007 | FY 2008 | FY 2009 | FY 2010 Approved |
|---|---|---|---|---|---|---|---|---|---|---|---|
| ■ Osawatomie State Hospital | 167 | 177 | 178 | 168 | 152 | 167 | 166 | 170 | 169 | 176 | 176 |
| ■ Rainbow Mental Health Facility | 30 | 35 | 41 | 37 | 41 | 40 | 41 | 41 | 44 | 50 | 50 |
| ▨ Larned State Hospital | 282 | 252 | 212 | 282 | 304 | 301 | 326 | 413 | 448 | 455 | 477 |

## State Developmental Disabilities Hospitals



| | FY 2000 | FY 2001 | FY 2002 | FY 2003 | FY 2004 | FY 2005 | FY 2006 | FY 2007 | FY 2008 | FY 2009 | FY 2010 Approved |
|---|---|---|---|---|---|---|---|---|---|---|---|
| ■ Kansas Neurological Institue | 189 | 186 | 184 | 177 | 170 | 165 | 166 | 164 | 160 | 158 | 159 |
| ▨ Parsons State Hospital & Training Center | 189 | 195 | 194 | 190 | 188 | 195 | 194 | 195 | 194 | 192 | 198 |

Kansas Legislative Research Department

October 13, 2009

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# KANSAS LEGISLATIVE RESEARCH DEPARTMENT

010-West–Statehouse, 300 SW 10th Ave.
Topeka, Kansas 66612-1504
(785) 296-3181 ◇ FAX (785) 296-3824

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October 14, 2009

## JOINT COMMITTEE ON HOME AND COMMUNITY BASED SERVICES OVERSIGHT: OVERVIEW OF THE FACILITIES CLOSURE AND REALIGNMENT COMMISSION

### Background

- The Facilities Closure and Realignment Commission was created by the Governor in Executive Order 09-01
- The Commission's charge is to "study and evaluate the closure and/or realignment of state facilities, and alternative uses of such facilities
- The Commission is to make its final recommendations to Gov. Mark Parkinson by December 2009
- There facilities for review include but are not limited to:
  - Kansas School for the Deaf
  - Kansas School for the Blind
  - Kansas Neurological Institute
  - Parsons State Hospital and Training Center
  - Rainbow Mental Health Facility

### Facilities Closure and Realignment Commission Action and Discussion to Date

*In general:*

- The commission has toured each facility mentioned as well as heard overviews from facility staff and public hearings
- The commission rejected the idea of closing either the School for the Blind or the School for the Deaf, but wants to pursue putting the separate schools on the same campus
- "Co-locating" the two schools could reduce operating costs, although they maintained that the two school populations would remain separated to provide the special instruction tailored to each group

*Items of note concerning State hospitals:*

Rainbow Mental Health Facility

- KVC Behavioral HealthCare, indicated an interest in the Rainbow Mental Health Facility building

Joint Home and Community Based Services
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- KVC is planning to develop a psychiatric hospital facility in close proximity to KU Med-Center

Developmental Disabilities Hospitals

- Parsons could accommodate 40 of the 156 residents currently at KNI

- KNI could handle 39 of the Parsons residents. If Parson is closed, the remainder would be expected to live in smaller communities

- SRS Secretary Jordan testified that he had participated in the closure of the Winfield State Hospital and there are three barriers for those with developmental disabilities that must be overcome:
  1. Choice – parents and guardians must be given choices
  2. Challenging behaviors
  3. Complex medical issues

- Challenges/concerns discussed by the committee concerning closure included:
  1. Difficulty to retain direct care staff because of pay and supervision
  2. Employees must be trained and paid well; Salaries and benefits must be funded appropriately
  3. Care for those with dual diagnosis or acute health care needs must still be available
  4. Creating options for clients to go back to their home communities instead of the community where the closure takes place
  5. Moving the workforce to the community with clients
  6. Difficulty in finding people who specialize in care for medically fragile and those with dual diagnosis.

## Upcoming Facilities Closure and Realignment Commission Meeting

- The next meeting will be Monday, October 26th and Tuesday, October 27th

- Topics of discussion will be:
  1. Kansas Neurological Institute
  2. Parsons State Hospital
  3. The Rehabilitation Center for the Blind
  4. Rainbow Mental Health Facility

- Prior to this meeting, the Commission Chair requested the following information be provided:
  1. Admissions projections: If the current system stayed on course of the last 5-10 years where would it be in the future?
  2. Would community based services be able to handle the increased number of clients?
  3. How many people chose to stay in the Winfield area following the hospital's closing?
  4. What are alternative uses for the buildings if facilities were closed?
  5. General information on employees' right of first refusal and salary rates

**KANSAS LEGISLATIVE RESEARCH DEPARTMENT**

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http://www.kslegislature.org/klrd

October 13, 2009

## Medicaid Program – Home and Community Based Services (HCBS) Waivers

### Advance Notice of Proposed Amendments to Section 1915(c) of the Federal Social Security Act

**Background:** Section 1915(c) of the federal Social Security Act was initially passed in 1981. It authorizes the Secretary of Health and Human Services to waive certain Medicaid requirements so that a state may offer HCBS to state-specified groups of Medicaid beneficiaries who meet a level of institutional care as provided for in the Medicaid State Plan. The Centers for Medicare and Medicaid Services (CMS) has supported state efforts to serve individuals in the least restrictive setting possible.

**Current Situation:** Currently, states must develop separate 1915(c) waivers to serve more than one of the targeted waiver populations – aged or disabled; mentally retarded or developmentally disabled; and mentally ill. There are approximately 350 HCBS waivers serving more than one million individuals. In Kansas, there currently are six waivers including: physically disabled, developmental disabilities, technology assistance, traumatic brain injury, autism, and frail elderly.

**Purpose of Amendments:** To remove a current regulatory barrier which will then allow states to design 1915(c) waivers based on needs rather than on diagnosis or condition; to more effectively define "home" and "community."

***Designing 1915(c) Waivers.*** The proposed amendments would:

- Provide an option to states to combine or eliminate the existing three permitted waiver targeted groups with the intent of increasing a state's ability to design service packages based on need, rather than on diagnosis or condition;
- Permit states to combine any of the three target groups in one waiver or to offer waiver services to groups defined differently from the pre-defined targeted groups;
- Provide additional flexibility to states but not mandate changes to state criteria;
- Continue to require states to determine that, without the waiver, participants would require an institutional level of care; and
- Continue to require states to meet waiver cost-neutrality requirements.

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Joint Home and Community Based Services
Date: 10/14/09
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***Home and Community-Based Services Expectations.*** The proposed amendments also would better describe the expectations for waiver participants being served in the home and community. Specifically, the proposed amendments would add a requirement that individuals receiving HCBS waiver services must reside in the home or community, in accordance with either of the following two criteria:

- Participant resides in a home or apartment not owned, leased or controlled by a provider of any health-related treatment or support services; or
- Participant resides in a home or apartment owned, leased or controlled by a provider of one or more health-related treatment or support services that meets standards for community living as defined by the state and approved by the Secretary of Health and Human Services. The standards for community living are to optimize participant independence and community integration, promote initiative and choice in daily living, and facilitate full access to community services.

  Criteria for the standards for home and community living will not be specified in the regulations but interested stakeholders are being solicited to work with CMS to develop policy guidelines for state definitions. The intent of the guidelines will be to create the necessary conditions so that individuals are able to reside in person-centered, home-like environments.

  Other anticipated regulatory changes would include methods that states may follow to identify appropriate financing mechanisms for reducing the size of existing larger residences; divesting themselves or helping providers divest themselves of sizable properties; and assisting providers' transition to smaller, more individualized settings.

**Comment Period:** CMS specifically requested comments on how streamlining the waiver target population process could improve a state's ability to design service packages based on need, rather than diagnosis or condition; to serve individuals requiring an institutional level of care; and to facilitate compliance with the Americans with Disabilities Act of 1990. Comments also were requested concerning what states can do to improve their systems to ensure that the settings where services are rendered are truly home and community-based in nature and that individuals are offered meaningful opportunities for community living. Additionally, comments were requested on what impact this focus might have on federally recognized tribes.

The comment period closed on August 21, 2009; 318 comments were submitted. Of those submissions, a total of 17 comments could be identified readily as being submitted by individuals or organizations in Kansas. There were two submissions in favor of a potential waiver consolidation, and the remaining 15 were opposed to such a consolidation.

Planning Unit, U.S. Environmental Protection Agency, EPA New England Regional Office, One Congress Street, Suite 1100 (CAQ), Boston, MA 02114–2023, telephone number (617) 918–1664, fax number (617) 918–0664, e-mail *Burkhart.Richard@epa.gov.*

Dated: June 12, 2009.

**Ira W. Leighton,**

*Acting, Regional Administrator, EPA New England.*

[FR Doc. E9–14604 Filed 6–19–09; 8:45 am]

BILLING CODE 6560–50–P

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## DEPARTMENT OF HEALTH AND HUMAN SERVICES

## Centers for Medicare & Medicaid Services

## 42 CFR Part 441

**[CMS–2296–ANPRM]**

**RIN 0938–AP61**

## Medicaid Program; Home and Community-Based Services (HCBS) Waivers

**AGENCY:** Centers for Medicare & Medicaid Services (CMS), HHS.

**ACTION:** Advance notice of proposed rulemaking.

**SUMMARY:** This advance notice of proposed rulemaking announces the intention of CMS to publish proposed amendments to the regulations implementing Medicaid home and community-based services waivers under section 1915(c) of the Social Security Act and solicits advance public comments on the merits of providing States the option to combine or eliminate the existing three permitted waiver targeting groups, and on the most effective means to define home and community.

**DATES:** To be assured consideration, comments must be received at one of the addresses provided below, no later than 5 p.m. on August 21, 2009.

**ADDRESSES:** In commenting, please refer to file code CMS–2296–ANPRM. Because of staff and resource limitations, we cannot accept comments by facsimile (FAX) transmission.

You may submit comments in one of four ways (please choose only one of the ways listed):

1. *Electronically.* You may submit electronic comments on this regulation to *http://www.regulations.gov.* Follow the instructions under the "More Search Options" tab.

2. *By regular mail.* You may mail written comments to the following address only: Centers for Medicare & Medicaid Services, Department of Health and Human Services, Attention: CMS–2296–ANPRM, P.O. Box 8016, Baltimore, MD 21244–1850.

Please allow sufficient time for mailed comments to be received before the close of the comment period.

3. *By express or overnight mail.* You may send written comments to the following address only: Centers for Medicare & Medicaid Services, Department of Health and Human Services, Attention: CMS–2296–ANPRM, Mail Stop C4–26–05, 7500 Security Boulevard, Baltimore, MD 21244–1850.

4. *By hand or courier.* If you prefer, you may deliver (by hand or courier) your written comments before the close of the comment period to either of the following addresses:

a. For delivery in Washington, DC—Centers for Medicare & Medicaid Services, Department of Health and Human Services, Room 445–G, Hubert H. Humphrey Building, 200 Independence Avenue, SW., Washington, DC 20201

(Because access to the interior of the Hubert H. Humphrey Building is not readily available to persons without Federal government identification, commenters are encouraged to leave their comments in the CMS drop slots located in the main lobby of the building. A stamp-in clock is available for persons wishing to retain a proof of filing by stamping in and retaining an extra copy of the comments being filed.).

b. For delivery in Baltimore, MD—Centers for Medicare & Medicaid Services, Department of Health and Human Services, 7500 Security Boulevard, Baltimore, MD 21244–1850.

If you intend to deliver your comments to the Baltimore address, please call telephone number (410) 786–7195 in advance to schedule your arrival with one of our staff members.

Comments mailed to the addresses indicated as appropriate for hand or courier delivery may be delayed and received after the comment period.

**FOR FURTHER INFORMATION CONTACT:** Mary Sowers, (410) 786–6814.

**SUPPLEMENTARY INFORMATION:**

*Inspection of Public Comments:* All comments received before the close of the comment period are available for viewing by the public, including any personally identifiable or confidential business information that is included in a comment. We post all comments received before the close of the comment period on the following Web site as soon as possible after they have been received: *http://www.regulations.gov.* Follow the search instructions on that Web site to view public comments.

Comments received timely will also be available for public inspection as they are received, generally beginning approximately 3 weeks after publication of a document, at the headquarters of the Centers for Medicare & Medicaid Services, 7500 Security Boulevard, Baltimore, Maryland 21244, Monday through Friday of each week from 8:30 a.m. to 4 p.m. To schedule an appointment to view public comments, phone 1–800–743–3951.

### I. Overview

We are issuing this advance notice of proposed rulemaking (ANPRM) to announce our intention to publish a proposed rule and solicit public comments on the changes necessary to provide States the option to design home and community-based services (HCBS) waiver programs serving more than one target population. We are particularly interested in receiving comments on how removal of the existing regulatory barrier regarding target groups may increase a State's ability to design service packages based on need, rather than diagnosis or condition. Furthermore, we are interested in receiving comments on how this change may affect the State's ability to serve individuals requiring an institutional level of care and may facilitate compliance with the Americans with Disabilities Act of 1990 (ADA). Title II of the ADA prohibits discrimination on the basis of disability and the Supreme Court ruled in *Olmstead* v. *L.C.*, 527 U.S. 581 (1999), that unnecessary institutionalization may constitute discrimination under the ADA. Many States have used the home and community-based services waiver as a component of their *Olmstead* compliance efforts and we are interested in receiving comments about how this change may affect these efforts. We are intending to propose this change in an effort to remove barriers to person-centered, needs-based service delivery methods. Consequently, we are also hoping to hear from interested parties regarding recommendations to strengthen person-centered principles and practices for the successful operation of any HCBS waiver program, including those that may serve individuals based upon identified needs, rather than diagnosis.

It is also our intention to publish as a part of the proposed rule requirements related to identifying the home and community-based character of the settings in which HCBS participants

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reside and/or receive services. During the development of the regulation for the new State plan HCBS benefit under section 1915(i) of the Social Security Act[1] (the Act), we received, as solicited, extensive comments on this issue. In preparation of this ANPRM, we took these comments into consideration and are contemplating publication of a proposed rule that would provide that States must define, and CMS approve, standards for home and community under HCBS waivers. Many commenters asked for a deliberative stakeholder process for developing criteria for home and community standards. This announcement provides advance notice of such a process in regard to HCBS waivers, and provides an opportunity for parties to express interest in participating.

## II. Background

Section 1915(c) of the Social Security Act (the Act) authorizes the Secretary of Health and Human Services to waive certain specific Medicaid statutory requirements so that a State may offer HCBS to State-specified group(s) of Medicaid beneficiaries who meet a level of institutional care that is provided under the Medicaid State plan. This provision was added to the Act by the Omnibus Budget and Reconciliation Act (OBRA) of 1981 (with a number of subsequent amendments). Regulations were published to effectuate this statutory provision, with final regulations issued in the mid-1990s.

### *A. Removing Regulatory Barrier To Designing 1915(c) Waivers Based on Needs Rather Than Diagnosis or Condition*

Section 1915(c) of the Act authorizes the Secretary to waive section 1902(a)(10)(B) of the Act, allowing States to waive comparability and target an HCBS waiver program to a specified Medicaid-eligible group or sub-group who would otherwise require an institutional level of care. A section 1915(c) waiver may currently only serve one of the three target populations identified in regulations at 42 CFR § 441.301. These three target groups are: Aged or disabled, or both; Mentally retarded or developmentally disabled, or both; and Mentally ill. States must develop separate 1915(c) waivers in order to serve more than one of these populations. This regulatory provision has contributed to States offering waivers with service packages tailored to different groups of individuals based upon diagnosis, rather than the individuals' actual need for support.

Because the three target populations outlined above are typically associated with a particular institutional level of care, the necessity to offer multiple separate waivers, is often framed as an inability to combine levels of care. For example, waiver costs for persons with developmental disabilities are most frequently compared to costs of Intermediate Care Facilities for Persons with Mental Retardation or conditions closely related to mental retardation (ICFs/MR), while waiver costs for persons who are aged or with physical disabilities are compared to nursing facility costs. However, the impediment to serving more than one target group through an HCBS waiver relates to the division between the target groups required in the regulation, not the associated institutional settings where those target groups would otherwise receive services but for the provision of HCBS. For example, some individuals with the need for mental health services may be appropriately served in the community at the nursing facility level of care.

Historically, in many cases pre-dating the 1915(c) HCBS waiver program, States have utilized a targeted approach to funding and budgeting for services for various populations. The CMS regulations published in the mid-1990s were modeled after those practices; the regulations reflect the funding approaches common in some State budgets. As the number of HCBS waivers across the country has grown to more than 350 waivers serving more than 1 million individuals, some States, with concurrence from stakeholder groups and individuals, have expressed a desire for the flexibility to combine these target groups in order to provide services based upon needs rather than diagnosis or condition, and for administrative relief from operating and managing multiple 1915(c) waiver programs.

We have considered these issues and intend to propose to change the regulations in 42 CFR subpart G to allow States the flexibility to combine any of the three target groups in one HCBS waiver, or possibly to choose to offer waiver services to groups defined differently from the pre-defined targeting groups. The intended proposed regulatory change would not mandate any change in State criteria for targeting HCBS waivers, it would provide additional State flexibility. We expect that States would continue to appreciate the narrow targeting permitted under section 1915(c) of the Act, particularly for populations with high needs or receiving unique services. Under the change we are planning to propose, States would still have to determine that without the waiver, participants would require institutional level of care, in accordance with section 1915(c) of the Act. Likewise, the intended proposal to provide additional targeting flexibility for States will not affect the cost-neutrality requirement inherent in section 1915(c) waivers.

In order to assure that individuals served by waivers targeting a broad range of conditions receive individualized care, we further plan to propose to require that: (1) The service planning process be person-centered, and (2) the services specified in the plan of care be based upon the needs of the individual, not an average need among one target group. In addition, we intend to update the language in the regulation related to the target groups to reflect more contemporary, person-first language.

We intend to propose this change to provide States with one additional tool to better serve their citizens, with person-centered delivery systems driven by need, not diagnosis or existing dedicated funding streams. A Federal regulatory change that permits combining targeted groups within one waiver, while optional for States and not an instantaneous change in State structures, would remove one barrier for States wishing to design waivers across various populations. We encourage comments on all aspects of the change we contemplate proposing, including its possible utility in enhancing State flexibility, minimizing administrative burden, facilitating compliance with the ADA, and facilitating a more needs-based service system.

### *B. Home and Community-Based Characteristics*

We are also intending to propose adjusting the regulations at 42 CFR subpart G to describe expectations with regard to waiver participants being served in the home and community. We believe such proposed requirements would increase choice by providing waiver participants with notice of housing alternatives, and would create greater demand and market incentive for person-centered residential settings. Our intended proposed changes would include methods that States may follow to identify appropriate financing mechanisms for reducing the size of existing larger residences, divesting themselves or helping their providers divest themselves of sizable properties, and assisting providers' transition to smaller, more individualized settings. We invite commenters to suggest other

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[1] 73 FR 18676, *http://edocket.access.gpo.gov/2008/pdf/08-1084.pdf.*

forms of technical assistance that CMS might provide to assist States in enhancing their efforts for optimal choice, control, and community integration for persons with disabilities and individuals who are aging.

Since the inception of the 1915(c) HCBS waiver program in the 1981, the Centers for Medicare & Medicaid Services (CMS) (formerly known as Health Care Finance Administration (HCFA)) has supported State efforts to serve individuals in the least restrictive setting possible. However, home and community have not been explicitly defined, and as a consequence, some individuals who receive HCBS in a residential setting managed or operated by a service provider have experienced a provider-centered and institution-like living arrangement, instead of a person-centered and home-like environment with the freedoms that should be characteristic of any home and community-based setting. For some years, we have attempted to address this problem indirectly through our review of State service definitions for HCBS, with limited success. Through this ANPRM, we are announcing our intention to propose to affirmatively identify expectations for characteristics of home and community-based settings.

The Deficit Reduction Act of 2005 created a new section 1915(i) of the Social Security Act. Section 1915(i) permits States to offer the HCBS specifically identified in section 1915(c)(4)(b) of the Act as a State plan option without requiring States to submit a waiver application. In addition to making HCBS available under the State plan, Congress expressed interest in assuring small, community-based home-like environments through statutory requirements in section 6071 of the DRA of 2005 for the Money Follows the Person Demonstration Program. This program authorized grants to States to increase the use of HCBS, rather than institutional services, and required that community-based residential settings include no more than a specific limited number of residents.

A regulatory change articulating CMS requirements for the nature of home and community-based residence under section 1915(c) HCBS waivers is necessary to ensure that the expectations for home and community characteristics are consistent across section 1915(c) of the Act and section 1915(i) authorities, and to ensure, most importantly, that individuals receiving HCBS have meaningful alternatives to institutional care, regardless of the section of the statute authorizing their services. Therefore, we are planning to propose adding to 42 CFR subpart G a requirement that individuals receiving HCBS waiver services must reside in the home or community, in accordance with either of two criteria enumerated below:

- Resides in a home or apartment not owned, leased or controlled by a provider of any health-related treatment or support services; or
- Resides in a home or apartment that is owned, leased or controlled by a provider of one or more health-related treatment or support services, and that meets standards for community living, as defined by the State and approved by the Secretary.

We believe that this wording takes into account the variety of living situations that should be exempt from evaluation, and avoids indirect indicators such as number of residents. Only living situations in which a paid provider of services has opportunity to affect the degree of independence and choice will trigger application of additional State-defined and CMS-approved standards for community living. Standards for community living are to optimize participant independence and community integration, promote initiative and choice in daily living, and facilitate full access to community services. To ensure that these goals are met, standards must be developed through strong stakeholder input. We would be interested in receiving comments regarding strategies that States could employ to solicit and incorporate strong stakeholder input in their efforts to define standards for community living.

We do not contemplate specifying criteria for home and community standards in the proposed regulation. We do solicit stakeholder interest in working with CMS to develop policy guidelines for State definitions.

The intent of these guidelines is to create the necessary conditions so that individuals are able to reside in person-centered, home-like environments where they can enjoy all of the liberties of community living. We recognize that it is difficult for a State to develop and monitor standards related to the individual's standing in a landlord/tenant relationship or in homeownership without inadvertently omitting an arrangement that could be ideal for a particular individual. Furthermore, we recognize that the criteria listed above may not address the possibility that some providers may undertake efforts to avert state-established standards. In light of the complexity of this matter, the long-standing HCBS waivers operating in the country currently, and the many existing efforts to ensure that individuals are provided services in the setting where they have maximum choice, control and individual liberties, CMS solicits public input on strategies to address this issue of maximum individual choice and control for the 1915(c) waiver participants. We solicit comments on pathways that States may take to improve their systems to ensure that the settings where services are rendered are truly home and community-based in nature, and that individuals are offered meaningful opportunities for community living. In addition, we solicit input on the potential impact of this issue on federally recognized tribes. We recognize that States will require assistance and technical guidance as they make changes, and also solicit comments on the nature of guidance and assistance that may be needed.

## III. Intentions of This Notice

We encourage comments that assist us in determining all implications of our contemplated proposed regulatory changes, and to assist us in constructing the regulations in a manner that provides appropriate guidance and incentives to result in meaningful, positive change for the nearly one million individuals currently served through 1915(c) HCBS waivers.

## IV. Response to Comments

Because of the large number of comments we normally receive on a proposed rule, we are not able to acknowledge or respond to them individually. However, we will consider all comments we receive by the date and time specified in the **DATES** section of this advance notice of proposed rulemaking, and will address these comments in any proposed regulation that results from this advance notice.

## V. Collection of Information Requirements

This document does not impose information collection and recordkeeping requirements. Consequently, it need not be reviewed by the Office of Management and Budget under the authority of the Paperwork Reduction Act of 1995.

**Authority:** Secs. 1102 and 1871 of the Social Security Act (42 U.S.C. 1302 and 1395hh).

9-5

Dated: May 29, 2009.

**Charlene Frizzera,**

*Acting Administrator, Centers for Medicare & Medicaid Services.*

Approved: June 16, 2009.

**Kathleen Sebelius,**

*Secretary.*

[FR Doc. E9–14559 Filed 6–19–09; 8:45 am]

BILLING CODE 4120–01–P

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## DEPARTMENT OF TRANSPORTATION

## Pipeline and Hazardous Materials Safety Administration

## 49 CFR Part 107

**[Docket No. PHMSA–2008–0010 (HM–208G)]**

**RIN 2137–AE35**

# Hazardous Materials Transportation; Miscellaneous Revisions to Registration and Fee Assessment Program

**AGENCY:** Pipeline and Hazardous Materials Safety Administration (PHMSA), DOT.

**ACTION:** Withdrawal of notice of proposed rulemaking.

**SUMMARY:** The Pipeline and Hazardous Materials Safety Administration (PHMSA) is withdrawing the notice of proposed rulemaking published under this docket on May 5, 2008 (73 FR 24519). Our revised estimates of unexpended balances from previous years and revenues expected to be generated at current registration fee levels indicate that an increase in registration fees is not necessary to fund the national Hazardous Materials Emergency Preparedness (HMEP) grants program at its authorized level of $28,318,000 for Fiscal Year 2009.

**FOR FURTHER INFORMATION CONTACT:** Deborah Boothe, Office of Hazardous Materials Standards, (202) 366–8553, or David Donaldson, Office of Hazardous Materials Planning and Analysis, (202) 366–4484, Pipeline and Hazardous Materials Safety Administration, U.S. Department of Transportation.

**SUPPLEMENTARY INFORMATION:**

## I. Background

The Hazardous Materials Emergency Preparedness (HMEP) grants program, as mandated by 49 U.S.C. 5116, provides Federal financial and technical assistance to States and Indian tribes to "develop, improve, and carry out emergency plans" within the National Response System and the Emergency Planning and Community Right-To-Know Act of 1986 (Title III), 42 U.S.C. 11001 *et seq.* The grants are used to develop, improve, and implement emergency plans; to train public sector hazardous materials emergency response employees to respond to accidents and incidents involving hazardous materials; to determine flow patterns of hazardous materials within a State and between States; and to determine the need within a State for regional hazardous materials emergency response teams. The HMEP grants program is funded by registration fees collected from persons who offer for transportation or transport certain hazardous materials in intrastate, interstate, or foreign commerce.

Congress reauthorized the Federal hazardous materials transportation law (Federal hazmat law; 49 U.S.C. 5101 *et seq.*) in 2005. The Hazardous Materials Transportation Safety and Security Reauthorization Act of 2005 (Title VII of the Safe, Accountable, Flexible, Efficient Transportation Equity Act—A Legacy for Users, Pub. L. 109–59, 119 Stat. 1144, Aug. 10, 2005) authorizes $28.3 million per year for the HMEP grants program and lowered the maximum registration fee from $5,000 to $3,000. The Consolidated Appropriations Act of 2008 (Pub. L. 110–161, 121 Stat. 2404, Dec. 26, 2007) set an obligation limitation of $28,318,000 for expenses from the HMEP fund, and the Administration's Fiscal Year 2009 budget requests $28,300,000 in support of HMEP activity.

## II. Current Rulemaking

To ensure full funding of the HMEP grants program for FY 2009, PHMSA proposed an increase in registration fees to fund the program at the $28.3 million level (73 FR 24519, May 5, 2008). For those registrants not qualifying as a small business or not-for-profit organization, we proposed to increase the registration fee from $975 (plus a $25 administrative fee) to $2,475 (plus a $25 administrative fee) for registration year 2009–2010 and following years. As explained in the NPRM, an existing surplus enabled us to delay an increase in registration fees, but we concluded that we would not be able to fund the HMEP grants program at the $28.3 million level in Fiscal Year 2009 without an increase.

We received 13 written comments in response to the NPRM from shippers and carriers and from the emergency response community, including the American Trucking Association (ATA), Council on the Safe Transportation of Hazardous Articles (COSTHA), Institute of Makers of Explosives (IME), International Association of Fire Chiefs (IAFC), National Association of SARA Title III Program Officials (NASTTPO), and Vessel Operators Hazardous Materials Association, Inc. (VOHMA).

We have recently re-examined our estimates for funding the HMEP grants program based on updated information from the Department of Treasury on the HMEP account carry-over balance, de-obligations of unused grant and administrative funds, increased enforcement of the registration requirements, and current registrant data, and we have further refined our estimates of revenues we anticipate collecting for registration years 2008–2009 (covering July 1, 2008 to June 30, 2009) and 2009–2010 (covering July 1, 2009 to June 30, 2010) at current registration fee levels. Based on this analysis, we have concluded that we will be able to fund the HMEP grants program at the $28.3 million level in Fiscal Year 2009 without an increase in registration fees. Accordingly, PHMSA is withdrawing the May 5, 2008, NPRM and terminating this rulemaking proceeding. Depending on appropriated and available funding for Fiscal Year 2010, we may initiate a future rulemaking to adjust registration fees for future registration years.

Issued in Washington, DC, on June 9, 2009 under authority delegated in 49 CFR part 106.

**Theodore L. Willke,**

*Associate Administrator for Hazardous Materials Safety.*

[FR Doc. E9–14569 Filed 6–19–09; 8:45 am]

BILLING CODE 4910–60–P

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## DEPARTMENT OF THE INTERIOR

## Fish and Wildlife Service

## 50 CFR Part 17

**[FWS–R6–ES–2009–0037; 92210–1117–0000–B4]**

# Endangered and Threatened Wildlife and Plants; 90-Day Finding on a Petition To Revise Critical Habitat for Eriogonum pelinophilum (Clay-Loving Wild Buckwheat)

**AGENCY:** Fish and Wildlife Service, Interior.

**ACTION:** Notice of 90-day petition finding and initiation of critical habitat review.

**SUMMARY:** We, the U.S. Fish and Wildlife Service (USFWS), announce a 90-day finding on a petition to revise critical habitat for *Eriogonum pelinophilum* (clay-loving wild buckwheat) under the Endangered

9-6

KANSAS
DEPARTMENT OF SOCIAL
AND REHABILITATION SERVICES

Don Jordan, Secretary

# Joint Committee on Home and Community Based Services Oversight

## October 14, 2009

# Home and Community Based Services Waivers

For Additional Information Contact:
Katy Belot, Director of Public Policy
Docking State Office Building, 6th Flc
(785) 296-3271

Joint Home and Community Based Services
Date: 10/14/09
Attachment: 10

KANSAS
DEPARTMENT OF SOCIAL
AND REHABILITATION SERVICES

# Joint Committee on Home and Community Based Services Oversight

## October 14, 2009

Chairman Bethell and members of the Committees, I am Don Jordan, Secretary of SRS. Thank you for the opportunity to appear before you today to discuss the Home and Community Based Services Waivers that are administered by SRS and the Money Follows the Person Grant. I will present information today regarding six Home and Community Based Service Waivers that provide services to persons with disabilities including the number of individuals served and funding for each of the programs. I will also provide information regarding the Money Follows the Person (MFP) Federal grant which impacts the HCBS waivers. I have included a chart with more detail on the waivers impacted by the MFP grant in Attachment A.

## Background

Medicaid waivers are Federally approved requests to waive certain specified Medicaid rules. For instance, Federal Medicaid rules generally allow states to draw down Federal Medicaid funds for services provided in institutions for persons with severe disabilities. Many of the community supports and services provided to persons with disabilities such as respite care, and attendant care services, are not covered by the regular Federal Medicaid program. Home and Community Based Services (HCBS) waivers give the state Federal approval to draw down Federal Medicaid matching funds for community supports and services provided to persons who are eligible for institutional placement, but who choose to receive services that allow them to continue to live in the community. The Center for Medicare and Medicaid Services (CMS) requires that the cost of services paid through HCBS waivers be, on the average, less than or equal to the cost of serving people in comparable institutions.

## Developmental Disability Waiver (MR/DD)

The MR/DD waiver serves individuals with a developmental disability. At this time there are 1,863 people on the waiting list receiving no waiver services and another 985 people receiving some services who are waiting for additional services. SRS maintains one statewide waiting list for HCBS-MR/DD services which includes both the unserved and the underserved. A person's position on the waiting list is determined by the request date for the service(s) for which the person is waiting. Each fiscal year, if funding is made available, people on the statewide waiting list are served, beginning with the oldest request dates at the top of the list. Currently, the persons at the top of the list have been waiting since June 27, 2005. Each year on the average, 208 people come off the waiver and these positions are filled by individuals in crisis situations and are the only people added to the waiver when additional funding is not made available.

10-2

## Physical Disability (PD) Waiver

On December 1, 2008 SRS implemented actions to control the growth of the PD Waiver. During FY 2008 the rate of growth in the waiver increased significantly. A rolling waiting list, allowing one person to come onto the waiver for every two persons that come off the waiver, was implemented not to cut the budget, but to avoid further overspending. With the implementation of a rolling waiting list approximately 7,300 individuals have been able to continue receiving services. New participants are added to the HCBS/PD waiver through the rolling waiting list, or who are added for crisis exceptions and reinstatements/transfers which count toward the one person on for two persons off calculation, or accessing services through the Money Follows the Person grant. As of October 1, 2009 there were 1,382 individuals on the PD Waiver waiting list.

SRS has been working with stakeholders to adjust program policies to assist in controlling the spending on the waiver. SRS is monitoring the number of requests for services, as well as the crisis situations, and will work with the Kansas Department on Aging to monitor the number of nursing facility admissions in order to determine if the development of a waiting list increases the number of nursing facility admissions.

## Traumatic Brain Injury (TBI) Waiver

The TBI Waiver is designed to serve individuals who would otherwise require institutionalization in a Head Injury Rehabilitation Hospital. The HCBS Waiver services are provided at a significant cost savings over institutional care and provide an opportunity for each person to live and work in their home communities. Each of these individuals is provided an opportunity to rebuild their lives through the provision of a combination of supports, therapies and services designed to build independence.

A significant difference in this program is that it is not considered a long term care program. It is considered a rehabilitation program and consumers are expected to transition to another program upon completion of rehabilitation. Individuals currently receive four years of therapy and, if at that time progress in rehabilitation is not seen, the individual is transitioned to another program. In FY 2009 the average length of stay in this program was 1.75 years. This number is based on the consumers who transitioned from services during FY 2009. There is currently no waiting list for this program.

## Technology Assisted (TA) Waiver

The TA Waiver is designed to serve children ages 0 to 22 years who are medically fragile and technology dependent requiring intense medical care comparable to the level of care provided in a hospital setting, for example, skilled nursing services. This program provides services to medically fragile children who would not be Medicaid eligible without the waiver and the waiver's ability to disregard parental income. The services provided through this waiver are designed to ensure that the child's medical needs are addressed effectively in the child's family home, thereby eliminating the need for long term and or frequent hospitalization for acute care reasons. There is no waiting list for this program. The TA Waiver served 381 children in FY2009 at a total cost of $ 18,462,707 and an average monthly cost per person of $ 4,038.

## Serious Emotional Disturbance (SED) Waiver

The Home and Community Based Services Waiver for Youth with a Serious Emotional Disturbance allows Federal Medicaid funding for community based mental health services for youth who have an SED and who are at risk of being placed in a state mental health hospital. The SED Waiver determines the youth's Medicaid eligibility based on his/her own income separate from that of the family's. Once the youth becomes a Medicaid beneficiary he/she may receive the full range of all Medicaid covered services including the full range of community mental health services. In addition, the youth is eligible for specific services only available to youth on the SED Waiver. The services offered through the SED Waiver and other community mental health services and supports are critical in assisting the youth to remain successfully in his/her family home and community. In FY 2009 the SED Waiver served 5,069 children at a total cost of $46,440,598 with an average monthly cost of $764 per child. This is based on FY 2009 claims processed through August 2009.

## Autism Waiver

The Autism Waiver is the newest of our HCBS waivers with the first funding approved for FY 2008. The target population for the Autism Waiver is children with Autism Spectrum Disorders (ASD), including Autism, Aspergers' Syndrome, and other pervasive developmental disorders – not otherwise specified. The diagnosis must be made by a licensed Medical Doctor or Ph.D Psychologist using an approved Autism specific screening tool. Children are able to enter the program from the age of diagnosis through the age of five. Children receiving services through this waiver would be eligible for placement in a state mental health hospital if services were not provided through the waiver. A child will be eligible to receive waiver services for a time period of three years with an exception process in place to allow children who demonstrate continued improvement to continue services beyond the three year limit.

The Autism Waiver was implemented on January 1, 2008. At that time 25 children were selected through a random process to receive services. The other applicants were placed on the waiting list. The 2008 Legislature approved funding for an additional 20 children to be served by the Autism Waiver in FY 2009. The waiver is now serving 45 children. There are 275 children waiting for services through this waiver. Since this waiver was implemented 53 children have aged off of the waiting list before services could begin. The total expenditure for the waiver in FY2009 was $486,675 for 47 children, with the average monthly cost per person being $863.

## Money Follows the Person (MFP) Grant

The federally funded Money Follows the Person (MFP) demonstration grant is designed to enhance participating states' ability to increase the capacity of approved HCBS programs to serve individuals that are currently residing in institutional settings. The benefit for Kansas is enhanced federal funding to create additional community capacity, facilitate private ICFs/MR voluntary bed closure, train staff, and ensure individuals have the supports in their homes to be successful, reducing the risk of re-institutionalization.

Target populations for this grant include persons currently residing in nursing facilities and intermediate care facilities for the mentally retarded. Individuals must have resided in the facility for a minimum of six months and have been Medicaid eligible for a minimum of 30 days to be eligible to move into the community.

SRS and KDOA are working together with the LTC Ombudsman office to identify individuals that are currently residing in qualified institutional settings and assist them to move into home settings of their choice.

SRS, as the lead agency for the demonstration grant, has partnered with the Kansas Department on Aging to develop benchmarks and implementation strategy. Additionally, KHPA is an integral partner as the Single State Medicaid Agency (SSMA).

The required Operational Protocol (implementation strategy) was approved by CMS in April of 2008, and the transition planning process began immediately after receiving the approval. The first actual move dates were July 1, 2008. The individuals transitioning into the community are representing the mentally retarded/developmentally disabled (MR/DD), traumatic brain injury (TBI), physically disabled (PD) and elderly populations groups. Kansans who have chosen community living include 19 persons with physical disabilities, 3 persons with a traumatic brain injury 68 individuals with developmental disabilities and 16 persons that are elderly.

The MFP movement report, which includes data on numbers of individuals transferred from institutions to community based care and the resultant costs is enclosed as Attachment B. Deputy Secretary Ray Dalton will discuss this chart with you in the next portion of the Agenda.

This concludes my testimony. Thank you for allowing me to provide you with this information today. I will take any questions you may have.

KANSAS
DEPARTMENT OF SOCIAL
AND REHABILITATION SERVICES

10-6

# Overview of Medicaid Home & Community Based Services Waivers Operated by DBHS/CSS and KDOA

Updated 7-17-09

| **Long Term Care Services** | **DEVELOPMENTAL DISABILITY WAIVER** | **PHYSICAL DISABILITY WAIVER** | **TRAUMATIC BRAIN INJURY WAIVER** | **FRAIL ELDERLY WAIVER** (operated by KS dept. on Aging) |
|---|---|---|---|---|
| **Institutional Equivalent** | Intermediate Care Facility for Persons with Mental Retardation | Nursing Facility | Head Injury Rehabilitation Facility | Nursing Facility |
| **Eligibility** | ➢ Individuals age 5 and up<br>➢ Meet definition of mental retardation or developmental disability<br>➢ Eligible for ICF/MR level of care | ➢ Individuals age 16-64*<br>➢ Determined disabled by SSA<br>➢ Need assistance with the activities of daily living.<br>➢ Eligible for nursing facility care<br>**Those on the waiver at the time they turn 65 may choose to stay on the waiver* | ➢ Individuals age 16-65<br>➢ Have traumatic, non-degenerative brain injury resulting in residual deficits and disabilities<br>➢ Eligible for in-patient care in a Head Injury Rehabilitation Hospital | ➢ Individuals age 65 or older<br>➢ Choose HCBS<br>➢ Functionally eligible for nursing care<br>➢ No waiver constraints |
| **Point of Entry** | Community Developmental Disability Organization | Case management Entities | Case management Entities | Case management Entities |
| **Financial Eligibility Rules** | ➢ Only the individual's personal income & resources are considered<br>➢ For individuals under age 18, parent's income & resources are not counted, but are considered for the purpose of determining a family participation fee<br>➢ Income over $727 per month must be contributed towards the cost of care | ➢ Only the individual's personal income & resources are considered<br>➢ For individuals under age 18, parent's income & resources are not counted, but are considered for the purpose of determining a family participation fee<br>➢ Income over $727 per month must be contributed towards the cost of care | ➢ Only the individual's personal income & resources are considered<br>➢ For individuals under age 18, parent's income & resources are not counted, but are considered for the purpose of determining a family participation fee<br>➢ Income over $727 per month must be contributed towards the cost of care | ➢ Only the individual's personal income & resources are considered<br>➢ Income over $727 per month must be contributed towards the cost of care |

| | DEVELOPMENTAL DISABLITY WAIVER | PHYSICAL DISABLITY WAIVER | TRAUMATIC BRAIN INJURY WAIVER | FRAIL ELDERLY WAIVER (operated by KS dept. on Aging) |
|---|---|---|---|---|
| **Services/ Supports** Additional regular Medicaid services are provided | ➢ Assistive Services<br>➢ Day Services<br>➢ Medical Alert Rental<br>➢ Oral Health Services<br>➢ Sleep Cycle support<br>➢ Personal Assistant Services<br>➢ Residential Supports<br>➢ Supported Employment<br>➢ Supportive Home Care<br>➢ Temporary and Overnight Respite<br>➢ Wellness Monitoring<br>➢ Family/Individual Supports | ➢ Personal Services<br>➢ Assistive Services<br>➢ Sleep Cycle Support<br>➢ Personal Emergency Response<br>➢ Personal Emergency Response Installation<br>➢ Oral Health | ➢ Personal Services<br>➢ Assistive Services<br>➢ Rehabilitation Therapies<br>➢ Transitional Living Skills<br>➢ Sleep Cycle Support<br>➢ Personal Emergency Response<br>➢ Personal Emergency Response Installation<br>➢ Oral Health | ➢ Adult Day Care<br>➢ Assistive Technology<br>➢ Attendant Care Services<br>➢ Medication Reminder<br>➢ Nursing Evaluation Visit<br>➢ Oral Health<br>➢ Personal Emergency Response<br>➢ Senior Companion<br>➢ Sleep Cycle Support<br>➢ Wellness monitoring |
| **Average Monthly Number Persons Served FY 09** | 7188 | 7210 | 243 | 5706 |
| **FY 09 Expenditures (All funds)** | $292,751,554 | $139,080,583 | $10,220,974 | $71,848,012 |
| Estimated Average **Waiver** expenditure Mo/year | $3,394 / $40,728 | $1607/ $19,290 | $3,505 / $42,062 | $ 1,049/ $12,592 |
| Institutional Setting Total Cost / Annually Per Person | Private ICF/MR<br>$14,120,008/ $77,582<br>Public ICF/MR (combined)*<br>$52,187,753/$149,107 | Nursing Facilities<br>$368,357,893/ $34,054<br>(Includes persons who are aging) | Head Injury Rehab Facility<br>$8,475,601/ $282,520 | Nursing Facilities<br>$368,357,893/ $34,054<br>(Includes persons with Physical disabilities) |

(1)From KHPA Medicaid Assistance Report http://www.khpa.ks.gov/medicaid_reports/download/MARFY09.pdf; *KNI/Parsons FY 2009 Expenditures & Daily Census Data

Kansas Department on Aging
Martin Kennedy, Acting Secretary
Oct. 14, 2009

# HCBS OVERSIGHT COMMITTEE

## HCBS-FE ELIGIBILITY GUIDELINES

- **HCBS-FE waiver serves seniors 65 years of age or older**
- **Senior choice of HCBS/FE**
- **Must be functionally eligible for nursing home level of care**
- **Must meet Medicaid financial eligibility**

Joint Home and Community Based Services
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## POINT OF ENTRY

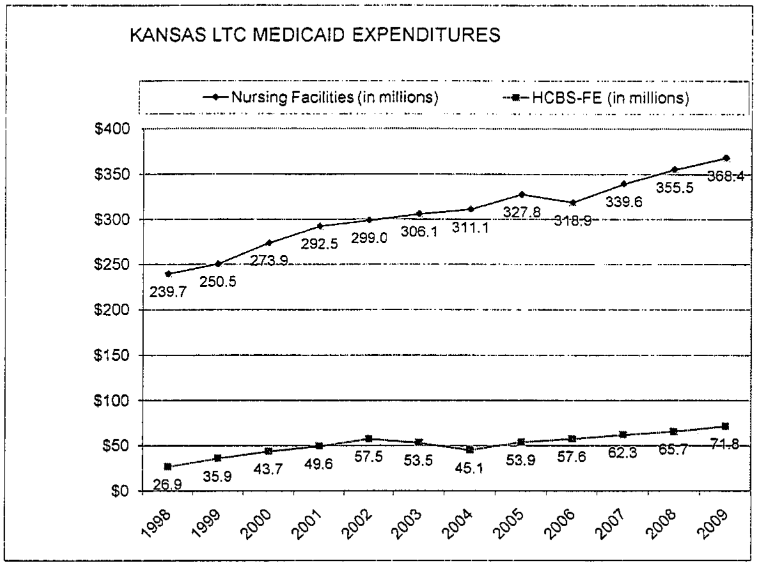
**Case Management Entities:**

- **+ 11 Area Agencies on Aging**
- **+ One independent case management entity**

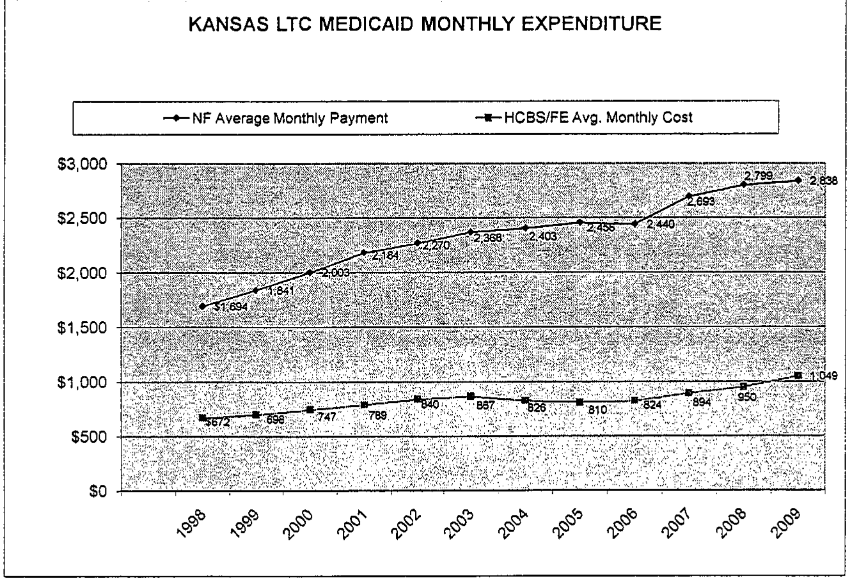
## HCBS/FE SERVICES

- × Adult Day Care
- × Assistive Technology
- × Attendant Care Services
- × Comprehensive Supports
- × Medication Reminder Service
- × Nursing Evaluation Visit
- × Oral Health Services
- × Personal Emergency Response System
- × Sleep Cycle Support
- × Wellness Monitoring

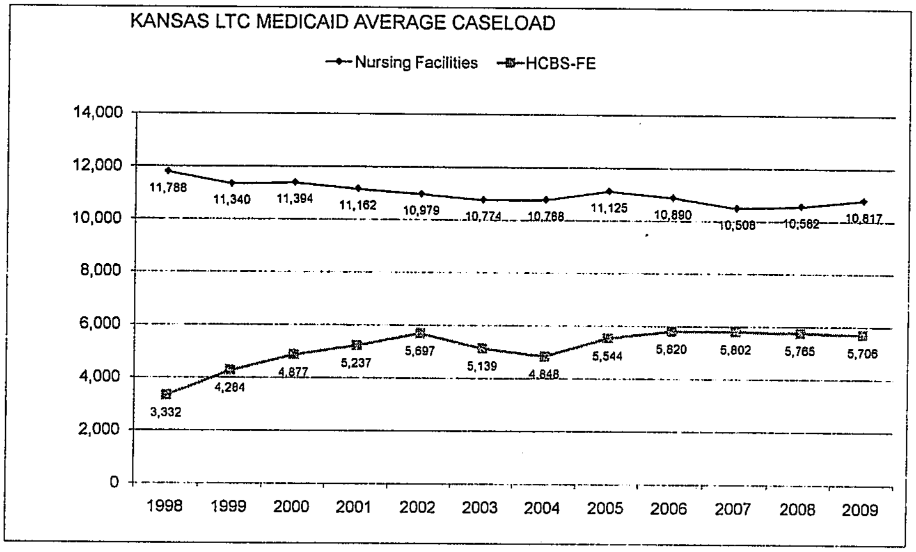
## LONG-TERM CARE EXPENDITURES



## MEDICAID MONTHLY EXPENDITURES



# MEDICAID AVERAGE CASELOAD



# KEY POINTS

- At this point, no waiting list but monitoring expenditures in SFY 2010
- 2011 HCBS-FE Enhancements:
  - Maintenance of effort
  - Telehealth service

## KEY POINTS

### 2011 HCBS-FE Enhancements

Maintenance of effort:
- $4.5M total funds ($1.6M SGF)
- Increased caseload-350 seniors
- $23 per month cost increase

Telehealth service:
- $1.1M total Funds ($383K SGF)
- Monitor chronic illnesses
- 500 seniors @ $6 per day

## KEY POINTS

+ 2011 Reduced Resources Budget

+ 3% HCBS-FE rate decrease

+ Total Reduction $2.1M ($741K SGF)

# MONEY FOLLOWS THE PERSON

KDOA works closely with SRS on the state and federal MFP programs

State MFP allows transfers at 90 days and does not limit housing option

Federal MFP allows transfer at 6 months and limits housing options

SRS Deputy Secretary Ray Dalton will present the quarterly MFP savings report

# Kansas Department of Social and Rehabilitation Services
# LONG-TERM CARE SUMMARY
# October 2009

| **DD INSTITUTIONAL SETTINGS** | **Number Served Start of SFY 2009** | **Average Cost Per Person** | **Estimated Costs** | |
|---|---|---|---|---|
| | | | **All Funds** | **SGF** |
| Private ICFs/MR | 236 | $ 72,036.00 | $ 17,000,496.00 | $ 5,732,567.25 |
| State DD Hospitals - SMRH | 358 | $ 154,893.00 | $ 55,451,694.00 | $ 18,698,311.22 |
| MFP ( # persons discharged into MFP program) **Private ICFs/MR** | -61 | | | |
| MFP ( # persons discharged into MFP program) **Public ICFs/MR SMRH** | -7 | | | |
| (# persons discharged NOT into MFP) **Private ICFs/MR** | -10 | | | |
| (# persons discharged NOT into MFP) **Public ICFs/MR SMRH** | -14 | | | |
| Sub-Total - **Private ICFs/MR** | 165 | | | |
| Sub-Total - **Public ICFs/MR -SMRH** | 337 | | | |
| New Admissions **Private ICFs/MR** | 13 | | | |
| New Admissions **Public ICFs/MR** | 21 | | | |
| Sub-Total - **Private ICFs/MR** | 178 | $ 72,036.00 | $ 12,822,408.00 | $ 4,323,715.98 |
| Sub-Total - **Public ICFs/MR -SMRH** | 358 | $ 154,893.00 | $ 55,451,694.00 | $ 18,698,311.22 |
| Net TOTAL Changes **Private ICFs/MR** | -58 | | $ (4,178,088.00) | $ (1,408,851.27) |
| Net TOTAL Changes **Public ICFs/MR** | 0 | | $ - | $ - |
| TOTAL DD Institutional Changes | -58 | | $ (4,178,088.00) | $ (1,408,851.27) |

| **DD WAIVER SERVICES** | **Number Served Start of SFY 2009** | **Average Cost Per Person** | **Estimated Costs** | |
|---|---|---|---|---|
| | | | **All Funds** | **SGF** |
| DD Waiver Community Services | 7456 | $ 39,324.00 | $ 293,247,924.00 | $ 98,883,199.97 |
| MFP | 68 | | | |
| Subtotal | 7524 | | | |
| *1 Change due to OTHER reasons | 72 | | | |
| Subtotal | 7596 | $ 39,324.00 | $ 298,705,104.00 | $ 100,753,231.58 |
| TOTAL NET CHANGES DD Waiver | 140 | | $ 5,457,180.00 | $ 1,840,161.10 |
| TOTAL NET CHANGES DD SYSTEM | | | $ 1,279,092.00 | $ 431,309.82 |

Joint Home and Community Based Services
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| FE / PD / TBI INSTITUTIONAL SETTINGS | Number Served Start of SFY 2009 | Average Cost Per Person | Estimated Costs All Funds | SGF |
|---|---|---|---|---|
| Nursing Homes | 18133 | $ 33,289.00 | $ 603,629,437.00 | $ 203,543,846.16 |
| MFP FE | -16 | | | |
| MFP PD | -19 | | | |
| MFP TBI | -3 | | | |
| non MFP community discharges | -8258 | | | |
| Other Discharges | -27889 | | | |
| Subtotal | -18052 | | | |
| Additional people (admissions) | 35989 | | | |
| Subtotal | 17937 | $ 33,289.00 | $ 597,104,793.00 | $ 201,343,736.20 |
| TOTAL NET INSTUTUTIONAL | -196 | | $ (6,524,644.00) | $ (2,200,109.96) |
| **FE / PD / TBI COMMUNITY SERVICES** | **Number Served Start of SFY 2009** | **Average Cost Per Person** | **Estimated Costs All Funds** | **SGF** |
| FE WAIVER | 5765 | $ 11,403.00 | $ 65,738,295.00 | $ 22,166,953.07 |
| PD WAIVER | 6849 | $ 16,896.00 | $ 115,720,704.00 | $ 48,040,144.00 |
| TBI WAIVER | 210 | $ 43,788.00 | $ 9,195,480.00 | $ 3,795,393.00 |
| FE MFP | 16 | | | |
| PD MFP | 19 | | | |
| TBI MFP | 3 | | | |
| SUBTOTAL FE | 5781 | | | |
| SUBTOTAL PD | 6868 | | | |
| SUBTOTAL TBI | 213 | | | |
| *2 Change due to OTHER reasons FE | 113 | | | |
| *3 Change due to OTHER reasons PD | 532 | | | |
| *4 Change due to OTHER reasons TBI | 81 | | | |
| SUBTOTAL FE | 5894 | $ 11,403.00 | $ 67,209,282.00 | $ 22,662,969.89 |
| SUBTOTAL PD | 7400 | $ 16,896.00 | $ 125,030,400.00 | $ 42,160,250.88 |
| SUBTOTAL TBI | 294 | $ 43,788.00 | $ 12,873,672.00 | $ 4,341,002.20 |
| | | | | |
| | | | | |
| TOTAL NET CHANGES FE//PD/TBI | 726 | | $ 14,458,875.00 | $ 4,875,532.65 |
| Total Net Changes FE//PD/TBI and Institution | | | $ 7,934,231.00 | $ 2,675,422.69 |
| | | | | |
| GRAND TOTAL - NET CHANGES | 808 | | $ 9,213,323.00 | $ 3,106,732.52 |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

| | |
|---|---|
| *1 Change due to OTHER reasons | Net number of persons added to waiver due to crisis, movement from other eligible programs |
| *2 Change due to OTHER reasons FE | Net number of persons added to waiver due to crisis, movement from other eligible programs |
| *3 Change due to OTHER reasons PD | Net number of persons added to waiver due to crisis, movement from other eligible programs |
| *4 Change due to OTHER reasons TBI | Net number of persons added to waiver due to new applications for services, crisis, movement from other eligible programs |
| ICFs/MR Private | Intermediate Care Facility for Persons with Mental Retardation - Privately Operated |
| ICFs/MR Public | Intermediate Care Facility for Persons with Mental Retardation - Public (Operated by the State of Kansas) also known as SMRH |
| SMRH | State Mental Retardation Hospital also known as a Public ICF/MR |
| DD Waiver | Community Services for persons with developmental disabilities funded by Medicaid |
| PD Waiver | Community Services for persons with physical disabilities funded by Medicaid |
| FE Waiver | Community Services for persons that meet the aging criteria funded by Medicaid |
| TBI Waiver | Community Services for persons with traumatic brain injuries funded by Medicaid |
| MFP | Money Follows the Person - a federally funded grant that serves persons moving from qualified institutional settings into qualified community settings |
| MFP - State | Money Follows the Person - state funded program |
| Non-MFP Community | Persons that exited institutional settings to live in the community - DID NOT qualify for MFP services |
| Other Discharges | Persons that exited institutional settings for other reasons ( death, transfer, non-qualifying stay - there are many possible reasons. |
| | |

Self Advocate
Coalition
of Kansas

Promoting empowerment and Independence.

My name is Kathy Lobb, I am the legislative liaison for the Self Advocate Coalition of Kansas.

There are a lot of people on the developmental disability waiting list; a way to provide more services to these people without costing Kansas more money is to close the state hospitals.

I am someone who has lived in an institutional school when I was young, but I now successfully live in the community. Sending me to live in an institutional school was a hard choice for my parents, and it was also a hard choice for them to allow me to live in the community again.

I know what it feels like to not have choices about my daily life like most people when I lived in an institutional school. But I also know the freedom of making my own choices when I transitioned into the community.

The transition from an institution into the community can be very scary. It was scary for me. It was scary for my parents. But it was a good transition.

I own my own home. I have a job in the community where I advocate for others on a daily basis. I am completely independent except for the supports I need for my disabilities. I am able to live my own life the way I do because I have the support of my family, friends and the community.

I am asking you to support people moving from institutions into the community so that they can make more choices like I do. I know it is a very scary transition for these people and their families, but it is a good transition. Sometimes the only way to help people start that transition is by closing the state hospitals. The supports these people need are available in the community, and they can be provided at a lower cost than in the state hospitals.

The cost savings from serving people in the community could be used to serve even more people in the community, or perhaps it could be used to raise the pay of people who work as personal care attendants resulting in even better services.

Kansas currently has a long waiting list of people who need services but aren't getting them. Closing the state hospitals provides an opportunity to serve individuals who are institutionalized in the community at a great cost savings to the state. These cost savings can be used to help eliminate the statewide waiting list so that more people can get the supports they need and thrive in the community like I do.

I am a taxpayer thanks to the supports that I receive. You have the opportunity to create more taxpayers like me by providing them the supports they need to live independently in the community.

Thank you for your time,

Kathy Lobb

Kathy Lobb

2518 Ridge Court Rm 236
Lawrence, KS 66046

1-888-354-7225
785-749-5588

Joint Home and Community Based Services
Date: 10/14/09
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**Kansas Council on Developmental Disabilities**

MARK PARKINSON, Governor
KRISTIN FAIRBANK, Chairperson
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*"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"*

# JOINT COMMITTEE ON HOME AND COMMUNITY BASED SERVICES OVERSIGHT
## Recommendation For Cost Neutral Funding Of DD Waiver
October 14, 2009

Madame Chairperson, Members of the Committee, I am providing this testimony on behalf of the Kansas Council on Developmental Disabilities regarding a cost neutral proposal to fund the waiting list for the Home and Community Based Services Waiver (HCBS) for Developmental Disabilities.

The Kansas Council is federally mandated and funded under the Developmental Disabilities Assistance and Bill of Rights Act of 2000. Members are appointed by the Governor and include primary consumers, immediate family, and representatives of the major agencies who provide services for individuals with developmental disabilities. Our mission is to advocate for individuals with developmental disabilities to receive adequate supports to make choices about where they live, work, and learn.

A Developmental Disability occurs before age 22, is life long, and results in major substantial functional limitation in three or more areas of major life activity such as self-care, mobility, and economic self-sufficiency. These disabilities require lifelong supports, they are not curable nor do persons usually get better as they get older.

### DD Waiting List

We currently have few resources and an Unserved (those who receive no services) DD Waiting List that grew from 1,120 in July 2004 to **1,733** in July 2009, a 35% increase in five years. In 1999 the waiting list for Developmental Disabilities was **393** *(Developmental Disabilities Summary for the Month of January, 1999).* When the Unserved Waiting List is added to the Underserved (those who receive some but not all services needed) of **1,812**, there are **3,545** persons with Developmental Disabilities in Kansas who receive no services or who need additional services. Yet we continue to spend **$54,183,589** on two facilities for 359 persons that cost an average of **$150,929** per person

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per year. The financial figures and state hospital numbers are from the 2009 Governor's Budget Report. Waiting list numbers are from the DD Monthly Summary published by the Department of Social and Rehabilitation Services and I have attached a spreadsheet that shows the number of people served and the numbers on the Unserved and Underserved Waiting lists for July of 1999, 2004, and 2009 (attached).

**Proposal for DD Waiver**

Our proposal is to close one or both of the remaining state hospitals for persons with Developmental Disabilities. When this was done in the mid 1990's, the funds were shifted to community based DD services and we were able to significantly reduce the HCBS DD Waiver.

People with developmental disabilities can and do live successfully in the community, even after many years in a state institution. I have personal experience with a cousin who is about my age and was at family gatherings until we reached high school. At that time (early 1960's) there were few community services available and he has a cognitive disability and serious behavior problems. His parents, not knowing what else to do, sent him to Kansas Neurological Institute where he lived for many years. As his parents grew older it became more and more difficult for them to drive to Topeka to see their son. Finally they talked to Jim Blume of Developmental Services of Northwest Kansas. Jim brought their son to Hays, where he now lives in an apartment. His parents can easily make the drive to Hays and see him. He is not "cured" and he is not easy to serve. However, with the right supports he is able to live in Hays, close to his parents and other family members, and is thriving, after having lived for almost 40 years in an institution.

He is not the only one to move to the community. I was involved with the closure of Winfield State Hospital in the mid 1990's. We heard many of the same issues that have been mentioned to you – the people living at Winfield were "too severe," too fragile", simply "too disabled" to ever survive outside an institution and it was not safe in the community. The Legislature and my Council jointly funded a study of what happened to these very fragile people when they left Winfield. We issued a grant to do the study and used an out of state consultant to ensure no conflict of interest. I have attached the outcomes report for you. Eighty-eight persons who lived at Winfield were visited in their last months at the facility and after one year of community living. James Conroy and his staff interviewed parents, guardians, and staff both in Winfield and in the community, then reviewed records and toured homes and day programs. The people who had developmental disabilities and participated in this study ranged in age from 8 to 79, with an average age of 43. They were 60% male, 40% female and 5% were minorities. All were identified as having "profound mental retardation [sic]", 51 were unable to walk, 17 had serious aggression problems, 23 exhibited severe self-abusive behaviors, 43 had major seizure disorders, 34 were blind and 33 had severe health problems. (Are People Better Off? Outcomes of the Closure of Winfield State Hospital, Final Report of the Hospital Closure Project, pp 20-21, December 1998 by James Conroy).

Clearly these people had multiple and significant disabilities. Equally clear is the actual documented improvement in their lives that resulted from movement to the community. I have provided you with the Report cited above – look at Table Three on page 24 – the verbal summary of Outcomes at Year One. Improvements were seen in adaptive behavior, challenging behavior, integration, choice making, qualities of life, health decreased use of medications, more family contacts – all resulting from moving to the community. Also seen was a decrease in public costs.

We surprised the consultant because he did not expect that we would be so successful, after all, no court had mandated the closure of Winfield. The State decided to do it after much study and discussion. We know how to close a facility such as Kansas Neurological Institute and Parsons State Hospital. We know how to take care of individuals with severe cognitive disabilities some of whom also have mental health and/or physical disabilities. This is not to say that the current state hospitals are bad or anything like the institutions of old. However, they are institutions and, as people who have developmental disabilities are like us in that they would like to live closer to family and friends in a home or apartment.

I also want to address the issue of safety since I hear this from many parents. For the past two to three years the Kansas Developmental Disabilities community has, as a part of an SRS program, been improving the system of monitoring the Community Developmental Disability Organizations (CDDOs). We now have regularly scheduled on-site monitoring visits to all CDDOs with participation of parents and consumers on each site team. People can and have been harmed in both community and institution settings. Unfortunately, there is no guarantee of complete safety in either setting but we are monitoring and have many checks and balances in the system.

We believe that hospital closure is something that should be done, both because people with developmental disabilities can, should, and want to be in a community setting and because it is a better use of our limited resources. The "savings" realized from closure being used to serve people with developmental disabilities in the community. Many of the people on our large waiting lists have been waiting for several years. We also need to increase the wages of those who provide direct care services to individuals in the community. They serve a vulnerable population and should receive adequate compensation. Community service providers need to attract and keep good employees. Finally, the federal Money Follows The Person grant could be used to assist persons in transitioning to the community.

I appreciate your time and patience and would be happy to answer any questions.

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785 296-2608 jrhys@windstream.net

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# Developmental Disabilities Monthly Summaries

## July of 1999, 2004, 2009

| Year | Number Served | % Inc | Number Unserved | % Inc | Number Underserved | % Inc |
|---|---|---|---|---|---|---|
| **1999** | 8,065 | | 393 | | No Record | |
| **2004** | 9,344 | 13.69% | 1,120 | 64.91% | 1,169 | |
| **2009** | 10,009 | 6.64% | 1,733 | 35.37% | 1,812 | 35.49% |

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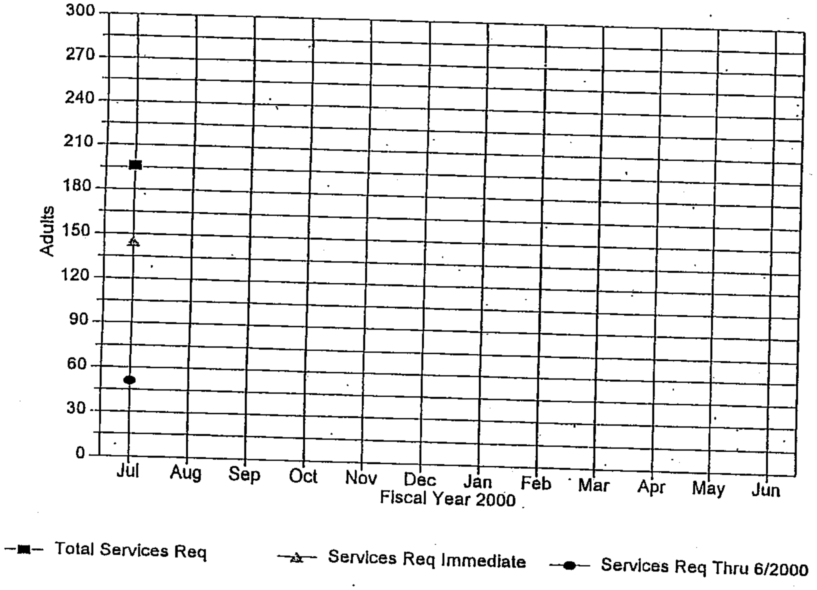
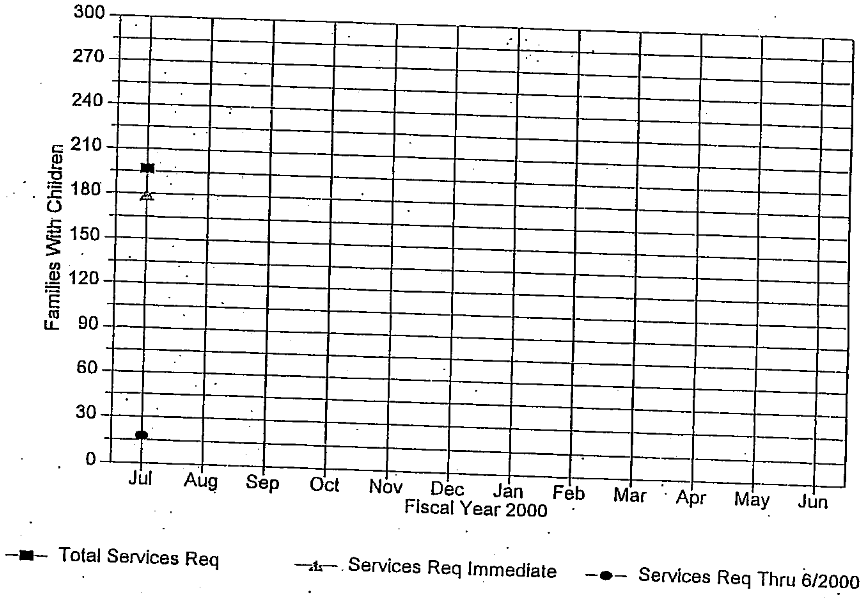
# Status of Service Requests
Fiscal Year 2000
Date Of Report: August 16, 1999

| | Jul | Aug | Sep | Oct | Nov | Dec | Jan | Feb | Mar | Apr | May | Jun | Net Change |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Adults Waiting | 196 | | | | | | | | | | | | 0 |
| Services Req Immediate | 145 | | | | | | | | | | | | |
| Services Req Thru 6/2000 | 51 | | | | | | | | | | | | |
| Families With Children | 197 | | | | | | | | | | | | 0 |
| Services Req Immediate | 179 | | | | | | | | | | | | |
| Services Req Thru 6/2000 | 18 | | | | | | | | | | | | |

## Adults Requesting Services



## Families With Children Requesting Services

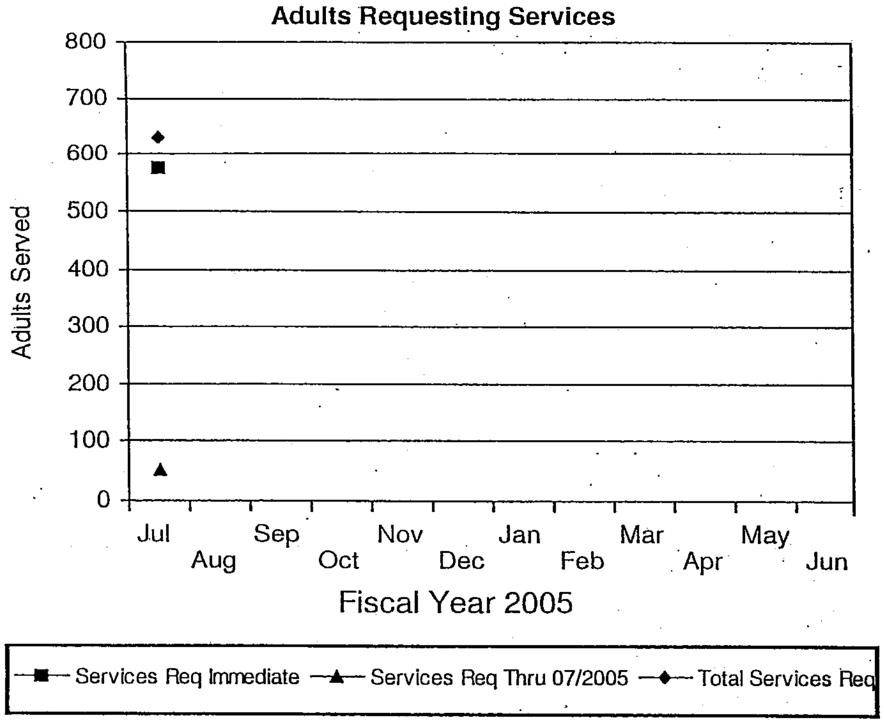


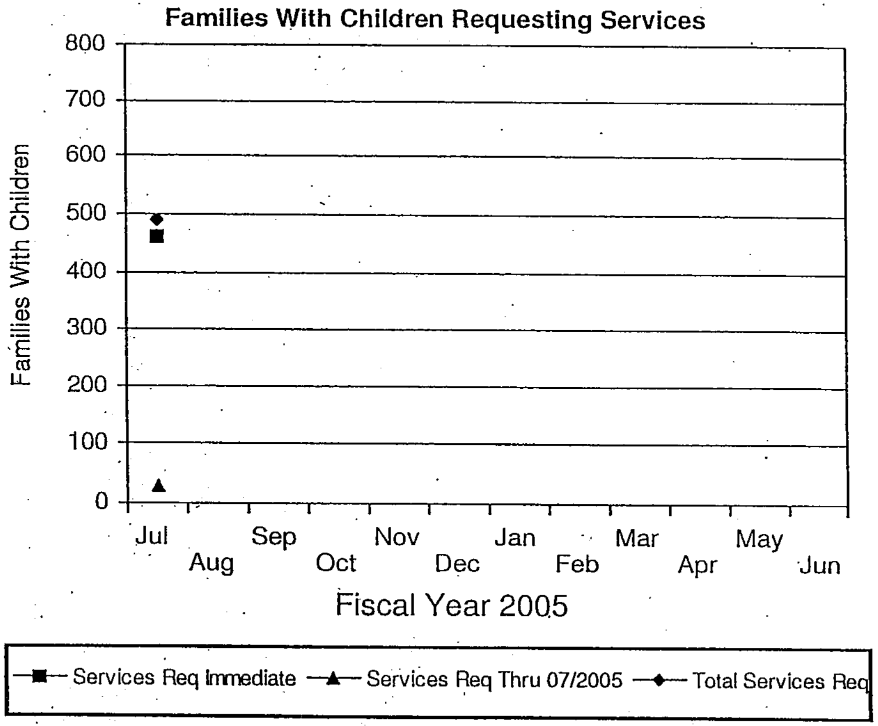
Data submitted by CDDOs

14-7

# Status of Service Requests
## Fiscal Year 2005
## Date Of Report: August 05, 2004

| | Jul | Aug | Sep | Oct | Nov | Dec | Jan | Feb | Mar | Apr | May | Jun | Net Change |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Adults Waiting | 629 | | | | | | | | | | | | 0 |
| Services Req Immediate | 576 | | | | | | | | | | | | |
| Services Req Thru 07/2005 | 53 | | | | | | | | | | | | |
| Families With Children | 491 | | | | | | | | | | | | 0 |
| Services Req Immediate | 460 | | | | | | | | | | | | |
| Services Req Thru 07/2005 | 31 | | | | | | | | | | | | |





*Data submitted by CDDOs*
*SRS Division of Health Care Policy*
*Policy Evaluation, Research & Training*
*August 5, 2004*

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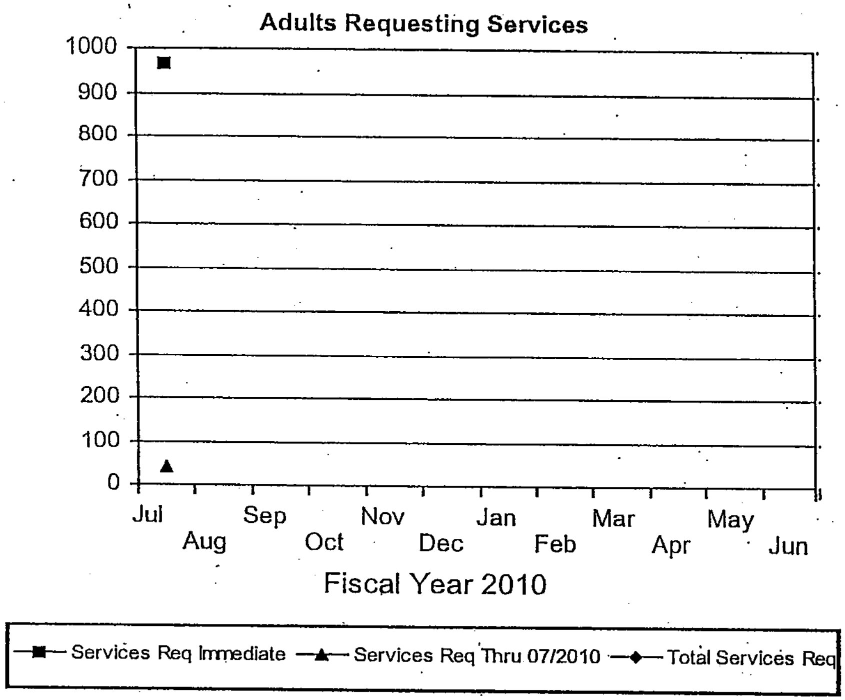
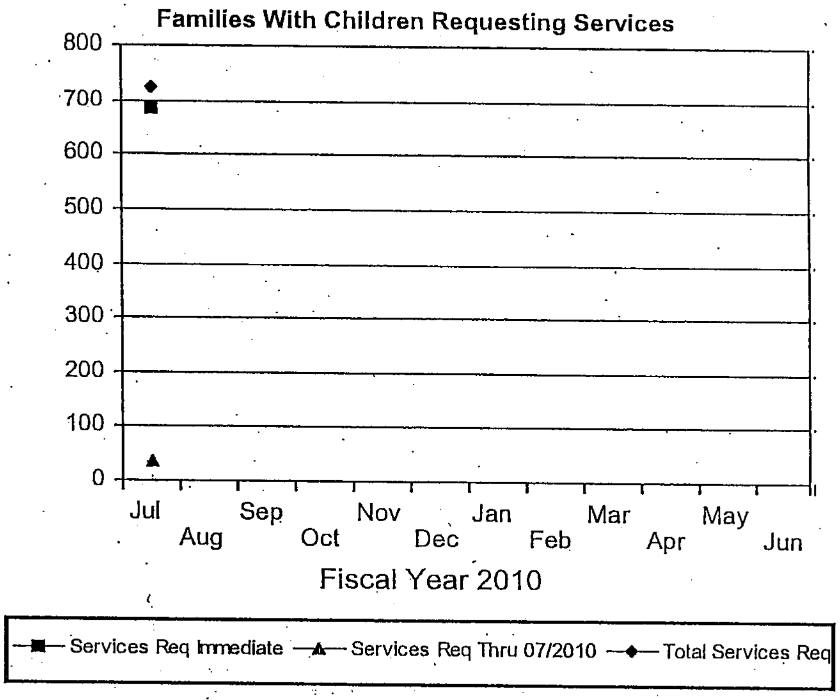
# Status of Service Requests
## Fiscal Year 2010
## Date Of Report: August 12, 2009

|  | Jul | Aug | Sep | Oct | Nov | Dec | Jan | Feb | Mar | Apr | May | Jun | Net Change |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Adults Waiting | 1009 |  |  |  |  |  |  |  |  |  |  |  | 0 |
| Services Req Immediate | 968 |  |  |  |  |  |  |  |  |  |  |  |  |
| Services Req Thru 07/2010 | 41 |  |  |  |  |  |  |  |  |  |  |  |  |
| Families With Children | 724 |  |  |  |  |  |  |  |  |  |  |  | 0 |
| Services Req Immediate | 687 |  |  |  |  |  |  |  |  |  |  |  |  |
| Services Req Thru 07/2010 | 37 |  |  |  |  |  |  |  |  |  |  |  |  |





*Data submitted by CDDOs*
*SRS Division of Health Care Policy*
*Policy Evaluation, Research & Training*
*August 12, 2009*

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

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

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

**Submitted by:**
*James W. Conroy, Ph.D.*
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**December, 1998**

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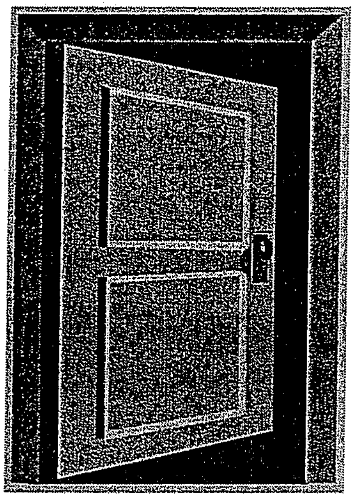
"In 1996, these people were surrounded by walls.
In 1998, they're surrounded by doors."



## 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 <u>Coffelt</u> years.

## Acknowledgements

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

# Table of Contents

# Executive Summary

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

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

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

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

# Verbal Summary of Outcomes at Year One

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

# 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

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(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).

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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.

# 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. Secondarily, 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

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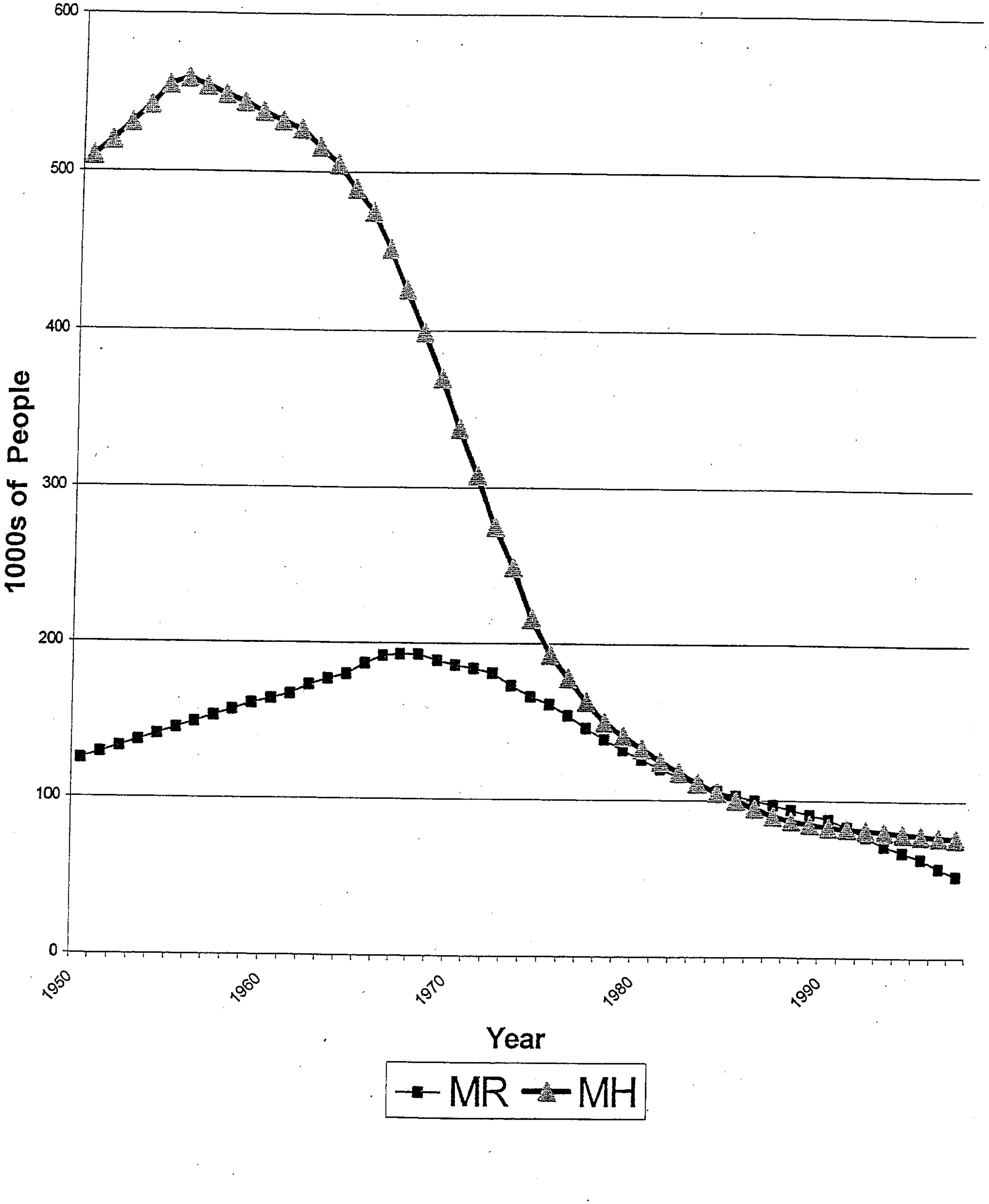
extraordinary confusion, as well as downright difficulty, in obtaining access to the information we needed in order to complete our mission.

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.

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



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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.

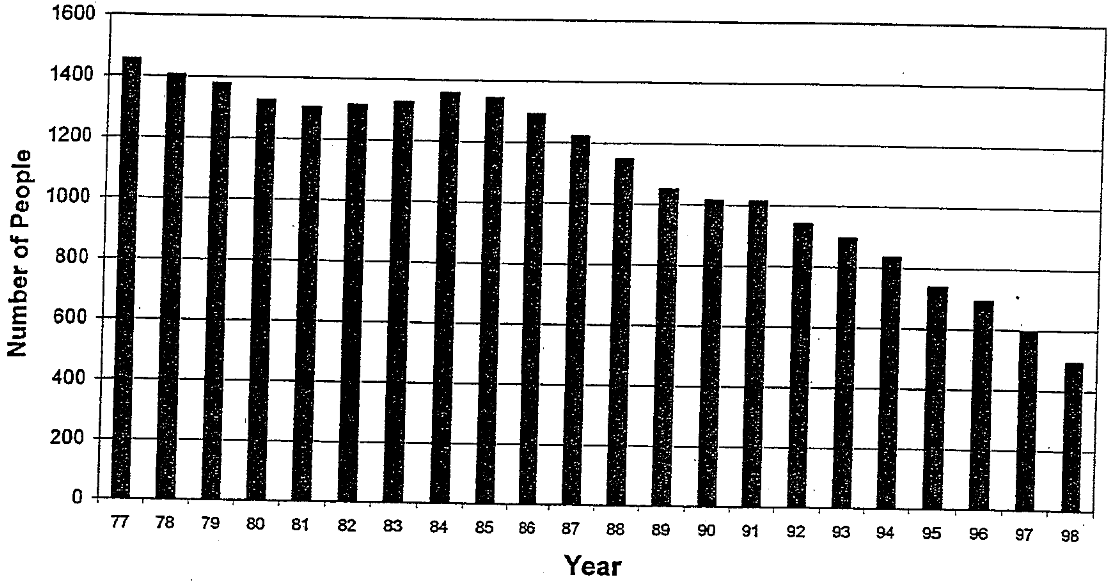

Figure 2:
The Decline of Institutional Populations in Kansas
1977 to 1998

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

| State | Time Period | Notes |
|---|---|---|
| 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 |

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The Kansas experience, which was <u>not</u> 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

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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 hs 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 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.

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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.

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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).

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## 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.

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## 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

| Quality Dimension | Pre | Post | t | df | P |
|---|---|---|---|---|---|
| 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 |

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# Table 3
# Verbal Summary of Outcomes at Year One

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

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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

| State | Number of Years | Time-1 Average Adaptive Behavior Score | Time-2 Average Adaptive Behavior Score | Gain on 100 Point Scales |
|---|---|---|---|---|
| | | | | |
| 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 |
| **Kansas** | **1 year** | **33.1** | **34.8** | **1.7** |

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.

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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 <u>percentage</u> 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 |
| **Kansas** | **1 year** | **78.6** | **81.3** | **2.7** |

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 in 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

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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

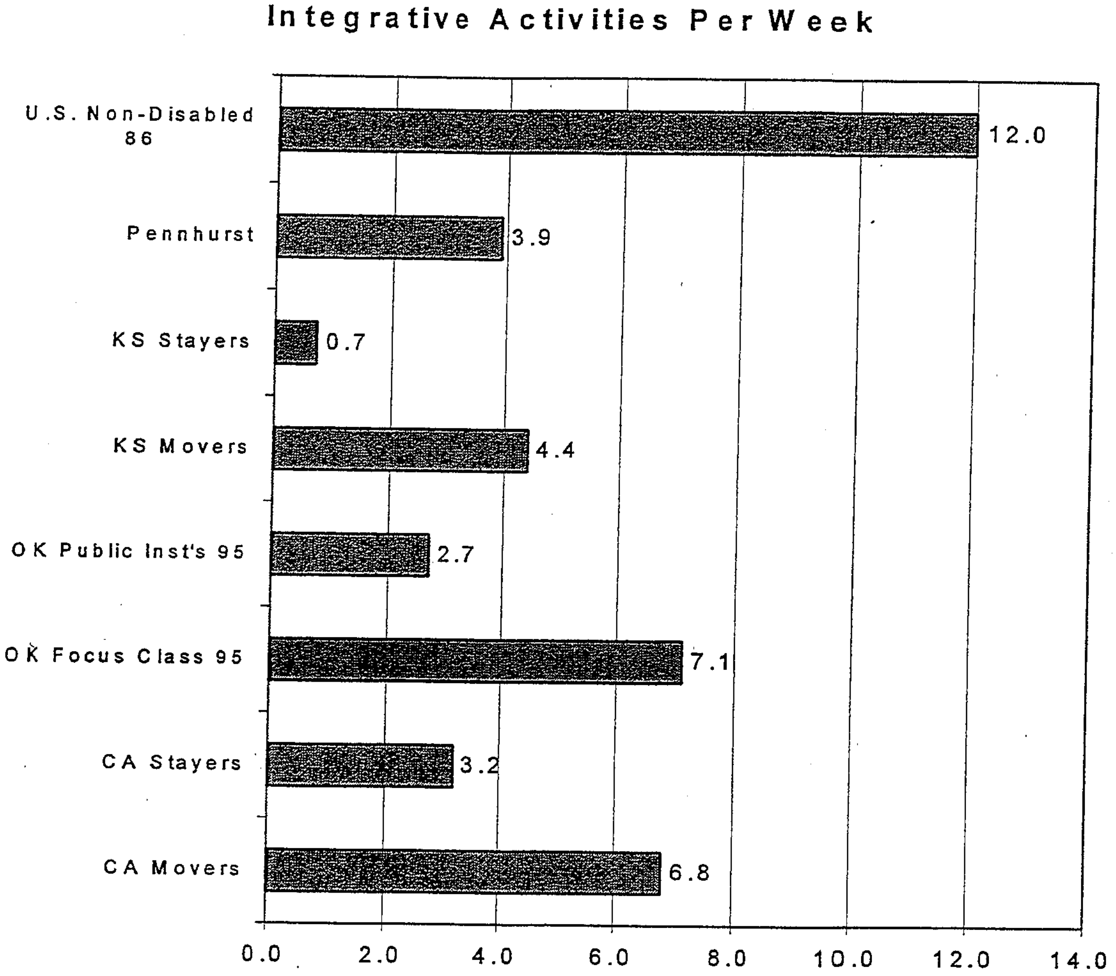

Figure 3 shows that the experiences of the Winfield Movers are not dissimilar to those of Movers in other states. The difference is that the Movers in California and Oklahoma have been out of their institutions longer, and hence have had more time to get into a rhythm of frequent outings.

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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.

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

| Dimension | Change |
|---|---|
| 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

| Dimension | Now | Then | P | Change |
|---|---|---|---|---|
| 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

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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 <u>each specific person</u> 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 if 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

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# Personal Life Quality Protocol
# Kansas Version 1.5

Developed by James W. Conroy, Ph.D.
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Rosemont, PA 19010

## 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.

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## General Information

1. ______________ First Name 2. ____ M.I. 3. ______________ Last Name

4. ______________ Social Security Number 5. ______________ 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. ______________ City or Town 11. ____ State 12. ______________ Zip Code

13. ______________ Home Telephone Number 14. ______________ Provider Number or Site Code

15. ______________ District With Which This Person Is Affiliated

16. ______________ Primary Respondent's Name 17. ______________ Title or Relationship

18. ______________ Visitor's Name 19. ______________ 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

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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

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## 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)

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## 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

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## 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 <u>present</u> 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 <u>participate</u> 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:

   ________________________________________

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10. NUMBER OF CASE MANAGER OR SUPPORT COORDINATOR CONTACTS: <u>About</u> 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 <u>primary</u> 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.

| | SHORT DESCRIPTION OF GOAL | CODE | Is This Goal Being Worked On Right Now?<br>0 = No<br>1 = Partial<br>2 = Fully | Have You Seen Any Progress In The Past Year?<br>1 = Much Regression<br>2 = Some Regression<br>3 = No Change<br>4 = Some Progress<br>5 = Much Progress |
|---|---|---|---|---|
| 13A. | ____________________ | _____ | 13F. _____ | 13K. _____ |
| 13B. | ____________________ | _____ | 13G. _____ | 13L. _____ |
| 13C. | ____________________ | _____ | 13H. _____ | 13M. _____ |
| 13D. | ____________________ | _____ | 13I. _____ | 13N. _____ |
| 13E. | ____________________ | _____ | 13J. _____ | 13O. _____ |

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## 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

15-54

## 14. Services/Supports

**INSTRUCTIONS**

- Minutes per day is only a rough estimate!!!
- Most people are awake around 840 minutes per day, so be sure the minutes don't ad more than that!
- 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?**<br>**ENTER 1 = YES 0 = NO** | **ROUGHLY How Many Minutes Per Day of this Service Does the Person Actually Receive?**<br>**ENTER MINUTES (0 if none)** |
|---|---|---|
| BASIC SELF-CARE SKILLS TRAINING . . . . . .<br>Teaching, not just helping; include hygiene, dressing, eating, domestic skills | 1 ____ | 13 ____ |
| COMMUNITY SKILLS TRAINING . . . . . . . . .<br>Shopping, use of identification, transportation, handling emergencies, etc. | 2 ____ | 14 ____ |
| APPROPRIATE SOCIAL BEHAVIOR TRAINING . . . .<br>Manners, interpersonal skills, etc. | 3 ____ | 15 ____ |
| COGNITIVE SKILLS TRAINING . . . . . . . . .<br>Letters, numbers, shapes, colors, reading, writing, arithmetic | 4 ____ | 16 ____ |
| OCCUPATIONAL THERAPY . . . . . . . . . . .<br>Delivered, designed, or supervised by an Occupational Therapist | 5 ____ | 17 ____ |
| PHYSICAL THERAPY . . . . . . . . . . . .<br>Delivered, designed, or supervised by a Physical Therapist | 6 ____ | 18 ____ |
| COMMUNICATION, SPEECH, & HEARING THERAPY . . .<br>Formal programs designed to improve communication abilities (devices included) | 7 ____ | 19 ____ |
| RECREATION TRAINING . . . . . . . . . . .<br>Learning ways to use leisure time | 8 ____ | 20 ____ |
| PSYCHOTHERAPY OR COUNSELING . . . . . . .<br>Delivered directly by a trained therapist | 9 ____ | 21 ____ |
| SEXUALITY EDUCATION, TRAINING, OR COUNSELING<br>Teaching person how to make safe and rewarding choices | 10 ____ | 22 ____ |
| PROGRAMS TO REDUCE CHALLENGING BEHAVIOR .<br>Systematic reinforcement programs of any kind | 11 ____ | 23 ____ |
| PERSONAL CARE ATTENDANT OR AIDE . . . . .<br>Providing help with physical or other needs | 12 ____ | 24 ____ |

15-55

# 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 <u>only</u>
   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

15-56

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

IN THE OPINION OF THE RESPONDENT, WHO IS THIS PERSON'S <u>CLOSEST</u> 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. (<u>NEVER</u> 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. ____________________ City or Town
5. ________ State
6. ________ Zip Code

7. ____________________ Telephone Number
8. ____________________ Language, if not English

9. <u>About</u> how often does this close relative / friend / guardian / guardian-advocate above see this person? (Accept times per week, or per month, and convert to <u>approximate</u> 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)

15-57

# Behavior

Adapted from the California Client Development Evaluation Report

Instructions

1. This information is to be obtained BY INTERVIEW from the staff (or other) perso 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 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 le fourths) of the time during the past 4 weeks.
6. If this typical behavior is performed with VERBAL prompts, give credit (unless in the item).
7. Do not give credit for behaviors performed with PHYSICAL guidance (unless other the item).
8. On any item, a "99" can be entered if the item is not applicable (usually becau disabilities are too severe), or if the person is too young, or if the person has display the behavior. The "99" choice is specially noted on items that have most 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

15-58

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

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## 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

15-63

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

15-64

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

15-65

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

15-66

## 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

15-67

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

15-68

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

15-69

## Decision Control Inventory

Ask the respondent to select a number from 0 to 10 to show who <u>actually</u> 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 <u>decline</u> 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

15-70

# 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%)

12.71

## 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 ____________________________________________

15-72

## 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

15-73

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

9.1 ___ ______ General orientation to the job (<u>before</u> 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. **<u>OPTIONAL</u>:** 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.)

15-74

# INFORMATION ABOUT THE HOME

## Individualized Practices Scale

INSTRUCTIONS

(1) Please complete each item by interviewing the respondent (staff person or othe 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

15-75

**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

15-76

# Quality of Life Changes

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

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. ___ |

15-77

# Personal Interview

(To Be Answered Only by the Person)

## INSTRUCTIONS

- These questions should be answered by the person (with the help of the person's helpers or interpreters, if needed or wanted).
- If appropriate and feasible, the interview should be conducted in private.
- It may make sense to have a friend, relative, or staff person present to assist please use your judgment.
- Try to interview the person, even if there is doubt about ability to respond; B
- **Never** attempt an interview if you have doubts about your safety.
- 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.
- 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.
- 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

15-78

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 <u>NOT</u> 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

15-79

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

15-80

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?

15-81

## 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:

15-82

# 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

15-83

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 <u>PURPOSE</u>, 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 | | | | | |

15-84

11\. NUTRITIONAL STATUS: Does this individual have any special dietary nee__.

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

15-85

15. SKIN CONDITION (Base these items on interviews with health care st 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, <u>how good</u> is this person's health care?
1 Very Poor
2 Poor
______ 3 Fair
4 Good
5 Excellent

15-86

# Home Physical Quality Scale

From Moos, Lemke, & Mehren, 1979, MEAP;
Modified by Temple University, 1983

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

15-87

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

15-88

## ELEMENTS OF NORMALIZATION

Adapted from Wolfensberger & Glenn, 1975

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.

15-89

# 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 |

DRC DISABILITY RIGHTS CENTER of KANSAS
EQUALITY ♦ LAW ♦ JUSTICE

# HCBS Committee – Revenue Neutral Ideas to Enhance HCBS DD Waiver Services through DD Hospital Closure; October 14, 2009

Members of the Committee, my name is Rocky Nichols. I am the Executive Director for the Disability Rights Center of Kansas (DRC). DRC is the federally mandated, officially designated protection and advocacy organization for Kansans with disabilities. DRC is a 501(c)(3) nonprofit, independent of both state government and disability service providers. We are not a provider of any of the HCBS DD Waiver services for which we advocate. We are a non-profit organization and stand to gain nothing from the closure of DD institutions. We were asked here to testify specifically how closing developmental disability (DD) institutions can be a revenue neutral way to enhance HCBS DD Waiver services.

**We are at a historic crossroads for services to Kansans with developmental disabilities (DD). Nearly 4,000 Kansans wait for DD services while we overfund our large-bed DD institutions. People with developmental disabilities, Kansas taxpayers and the State of Kansas cannot afford to continue to fund expensive, out-of-date, large-bed DD institutions (KNI and Parsons) *and* serve the needs of people with DD in community-based settings.**

If Kansas were to close both KNI and Parsons it would create a revenue neutral way pump millions of dollars into new HCBS DD Waiver services. We do not take the idea of closing both large-bed DD Institutions lightly. To close both institutions is a major task. It should be done carefully, over a reasonable period of time, and every dollar previously spent in the institutions must flow to the DD Waiver. Over a dozen states have closed either all their public or private DD institutions. As an overview of this issue I will pose a fundamental question to this Committee and propose an answer to that question.

**The question is: Why should this Committee propose closing both KNI and Parsons and use all the dollars as a revenue neutral way to enhance DD Waiver services?**

**I have three answers to that question, which will become the theme of my presentation**

1) **40 million dollars**
2) **358**
3) **4,000**

Joint Home and Community Based Services
Date: 10/14/09
Attachment: 16

**I will explain each answer below:**

**40 million dollars** = As I will show in this testimony, Kansas is spending 40 million more dollars on KNI and Parson (on average) than if the people were served on the DD Waiver.

**358** = 358 Kansans are served in KNI & Parsons. The overwhelming research and real-life experience with Winfield Hospital closure clearly proves that the 358 people currently served at KNI and Parsons will receive better care and better outcomes if proper funding is provided in the community.

**4,000** = Nearly 4,000 Kansans with developmental disabilities forced to wait for community services. If the extra 40 million was transferred to HCBS DD Waiver community services (along with the untold millions from the sale of the property, buildings, etc.), think of how many of the nearly 4,000 people waiting for services would get the life-saving, community based DD Waiver services that they need.

## 358 people (KNI/Parsons) = spending $40.4 million MORE than community

| **Place** | **Ave. # persons** | **Ave Cost per person** | **Total Cost** |
|---|---|---|---|
| *Total Average cost at KNI & Parsons* | *358* | *$148,526 (ave of KNI & Parsons)* | *$53,172,308* |
| *Total Average HCBS Costs for serving the 358 in the community* | *358* | *$35,663 (ave cost to serve on DD HCBS Waiver)* | *$12,767,354* |
| **Disparity & Higher Cost of Institution** | **N/A** | **Institution is $115,626 MORE per person** | **$40,404,954 MORE is being spent in institutions** |

**Imagine if KNI and Parsons were both closed, just like Winfield was successfully closed well over 10 years ago. That's upwards of $40.4 million more that can support enhanced services on the HCBS DD Waiver, provide better services, begin the process of eliminating waiting lists & increase community capacity.**

**Services are Better Delivered in the Community – Tens of Millions of Dollars can Transfer to the Community to Address the Waiting List -** DRC would further recommend that every dollar saved by closing the large-bed ICFs/MR go directly as new dollars into community-based HCBS DD Waiver services. Think of all the good the additional $40.4 million Kansas is spending in KNI and Parsons could do to serve those 358 people and the nearly 4,000 waiting for services in the community.

**Hospital closure should not be about saving money; Closure Contingent upon ALL the Money Flowing into the Community –** Medicaid and HCBS Waivers are life saving services for people with disabilities. They provide the most critical long-term care supports for Kansans with developmental disabilities and, equally important, they provide the dignity of living in the community. Hospital closure should be about spending tax dollars more wisely and targeting all the savings to fund community-based services. **That is why any closure of DD hospitals must be contingent upon having ALL the money flow to the community. ALL the money means not just the programmatic money; it means the sale of any real estate, buildings or other surplus property from KNI and Parsons. All the money means all the money. If you want to close institutions as a catalyst to improve community-based services for the 358 Kansans being served in DD institutions and the 4,000 forced on waiting lists by ensuring all the dollars flow into the community, then you will have DRC Kansas and many disability advocacy groups ready to help you. If, however, you want to close DD hospitals to save money and help the budget crunch, then we frankly don't want any part of that.**

## Why do we still have large-bed DD Institutions in Kansas?

You might be asking yourself, given these facts, why do we still have large-bed DD institutions? You would think that there has got to be a good reason for spending $40.4 million more to serve the 358 people with DD in institutions while nearly 4,000 Kansans with DD are forced to wait for services. **The needs of the persons with developmental disabilities in the institution must be dramatically higher to justify spending $40 million more (nearly 5 times the amount per person), right? Wrong.**

The fact is that the Kansans being served in expensive, out-of-date DD institutions are just like the Kansans being served in the community. For every person in a Kansas DD institutional setting, you can find someone with similar or more advanced needs being served in the community somewhere in Kansas or in our nation.

- The severity of a Kansan's developmental disability is determined by a thorough and complex "Tier score." The Tier levels of persons being served in large-bed DD institutions are strikingly similar to the Tier levels of those being served in the community. Key to keep in mind, the lower the Tier number the greater the severity of the disability and greater the need. The higher the Tier number, the lower the level of severity of the disability and the less assistance needed. According to 2004 figures from SRS (data from the most recent SRS task force report):
    - **DD Institution - 48% are Tiers 1-2, while 52% are Tiers 3-5** (note: the lower the Tier Score, the greater the need and greater the disability)
    - **HCBS DD Waiver services - 42% are Tiers 1-2 and 58% are Tiers 3-5.** These are *nearly identical* to institutional scores, and more Kansans with severe disabilities have been moved into the community since this study.

- The numbers are just as telling when you compare the *average* Tier of those served in the different settings (2004 data, more recent data will likely score more severe disabilities in the community):

| | |
|---|---|
| KNI | 2.0 Average Tier Score |
| Parsons | 3.0 Average Tier Score |
| Community Services | 3.07 Average Tier Score |

**121 Kansans "Tier 1" (the greatest severity, greatest needs) are at KNI and Parsons. In HCBS DD Waiver Residential services <u>alone</u> – 1338 Kansans "Tier 1" are thriving – well over 10 times the number.** For every 1 Kansan who is most severely disabled in KNI and Parsons you will find well over 10 with the same severity on the HCBS DD Waiver … and that's just HCBS DD Waiver Residential services. Those 1338 Tier 1 numbers does not include Day, In-Home Adult or In-Home Child Services. When you include those numbers, the number of total Tier 1 individuals is much higher (5/1/2009 SRS Figures).

- The vast majority of individuals formerly served by the Winfield DD Institution are now successfully being served in the community. Few transferred from Winfield to KNI or Parsons. If the majority of those formerly being served at the Winfield DD Institution are being served successfully in the community, if the needs of individuals are the same in the community as institutions, then why do we still need DD Institutions at all?

Again, you would think that Kansas would have a compelling reason for spending $40.4 million more to serve the 358 people in DD institutions while nearly 4,000 Kansans wait for services. **<u>It has to be the federal government forcing us to keep these antiquated DD institutions open with some arcane Medicaid entitlement rule, right?</u> <u>Wrong</u>.**

**Unlike Nursing Institutions, DD Institutions (ICFs/MR) are <u>NOT</u> a Medicaid entitlement**

- ICFs/MR are an <u>optional</u> service under federal Medicaid law. Therefore, Kansas could have a policy to close all <u>large-bed ICFs/MR institutional beds</u> and use the savings to provide tens of millions of new dollars for community-based services for Kansans with disabilities. **Closing all the large-bed ICFs/MR institutions would still allow Kansans with developmental disabilities to have <u>access to small-bed ICFs/MR and regional specialized, targeted capacity, like for those with significant behavior issues</u>.** It would enable the promise of the DD Reform Act to become a reality.

**In fact, public policy and the spirit of the law argue against institutions. We haven't had the political will to do the right thing with DD institutions. You can change that.**

- <u>Over a dozen states have closed either all their private or public Intermediate Care Facilities for persons with Mental Retardation (ICFs/MR)</u>. Closing both KNI & Parsons in an orderly manner and over a reasonable period of time is in line with the national consensus that is growing on this issue.
- In the landmark U.S. Supreme Court Olmstead decision, the high court made it clear that under the Americans with Disabilities Act (ADA) persons with disabilities have the right to reside in community based services in the most inclusive setting possible. The courts have said that unnecessary institutionalization is discrimination. 4,000 people waiting for services while we spend an additional $40 million on institutional level of care is absolutely unnecessary. Kansas has a legal requirement to comply with the ADA.

**So, why do we still have large-bed DD Institutions in Kansas?**
I can't think of a single effective argument, other then to protect state jobs or the local economic impact of closing the institutions, arguments that should be rejected outright. The real reason is that when you put people in institutions you end up perpetuating the need for the institution, instead of focusing on the needs of the people. Talking about economic impact, there are currently far more people on the waiting lists for HCBS DD Waiver services in the Topeka and Parsons areas than are being served in the two large institutions.

**Right Decision is for Kansas to Close All DD Institutions, but only if <u>ALL</u> the money flows to the DD Waiver** – It is not a question of which DD facility should be closed. The recommendation should not pit Topeka vs. Parsons. **The recommendation should be that Kansas' waiting list has grown far too long, we are dead last in our region in HCBS DD Waiver spending, and that we must have a new vision for the future of Kansas DD services.** This Committee should make the recommendation that the state can no longer afford to fund large-bed ICFs/MR, and that both KNI and Parsons should be closed in an orderly manner over a reasonable period of time, with all the dollars and proceeds targeted to HCBS DD Waiver services. The best way to do that is to have a date certain in the relatively near future where the state will eliminate the optional service under Medicaid for large-bed ICFs/MR, and close both these DD Institutions for good, in order to fund more effective, efficient and needed community based services. <u>Kansas should join the more than a dozen states that have closed either their public or private DD institutions (ICFs/MR).</u>

Thank you for the opportunity to provide information on this topic of revenue neutral ways to enhance HCBS DD Waiver services.

## Additional Information and Background on this issue:

**Community Capacity Must Expand in Kansas; Kansas has the Lowest DD Waiver Spending in out Region -** Kansas is last in our surrounding five-state region in the average amount spent per person, per year on DD HCBS Waiver services:

- Oklahoma $47,700 per person, per year
- Nebraska $44,500 per person, per year
- Colorado $40,200 per person, per year
- Missouri $36,700 per person, per year
- *Kansas $32,500 per person, per year*

(source: 2008 State of the State in Developmental Disability Services – a 50 State Comparison; David Braddock, University of Colorado; using 2006 numbers, the latest year for comparative data)
[NOTE: This national report uses 2006 numbers and a uniform method by which to calculate the average to ensure that they can compare the states.]

**Oklahoma spends nearly 50% MORE per person, per year on the DD Waiver than Kansas. Is it any wonder that we have a need to increase capacity at the community level in Kansas?**

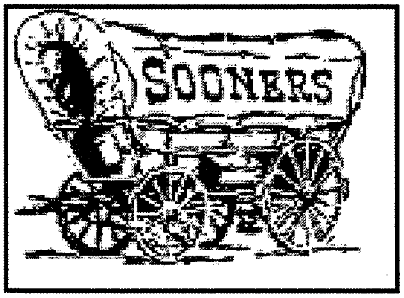
- The State of Kansas spends dramatically more per person on institutional services than community-based services, even when the level of support needed for the person is the same.
    - **Kansas spends $35,663 on average per year to serve a person with DD in the community on HCBS DD Waiver** (source: 2009 Gov. Budget Report, performance measures; comparison on costs & numbers served).
    - **Kansas spends on average nearly $150,000 to serve that SAME person with DD in state DD hospitals ($125,195 in Parsons State Hospital, $177,390 in KNI).** (sources: GBR, comparison on costs & numbers served).
    - **How does spending upwards of nearly FIVE TIMES the amount for Institutional Care vs. Community-Based Care deliver on the promise of the ADA? It does not.**

- Nearly 4,000 Kansans with Developmental Disabilities (DD) are waiting for some type of service while Kansas continues to overfund expensive DD institutions at KNI & Parsons.
    - HCBS DD Waiver Waiting List may grow to over 1,800 people without action by this Legislature, many of whom wait years for life saving services.
    - There are an additional upwards of 2,000 Kansans with DD on the "under"-served waiting lists, who though they may have cleared the initial waiting list, are provided *some* of the services they need, but put on a secondary waiting list for care that they absolutely need according to the results of states own assessment.

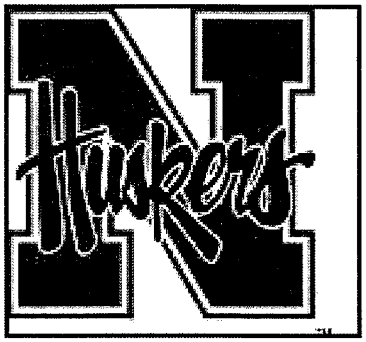
### More Data on Tier Scoring:

- From 2004 SRS Study - Average Maladaptive Scores also show that people with severe disabilities are being successfully served in community-based HCBS services (Maladaptive score is a number from 0-200 – the higher the number, the greater the severity of disability). KNI = 40.8; Parsons = 71.16; Private large-bed ICF/MR = 74.79; Community Services = 66.44.
- From 2004- Average Adaptive Scores (0-500; higher the score, greater the severity of disability). KNI = 399.83; Parsons = 209.70; Private large-bed ICF/MR = 227.95; Community Services = 210.73
- From 2004 - 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

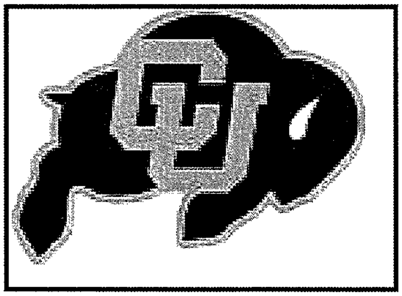
## 1. Oklahoma



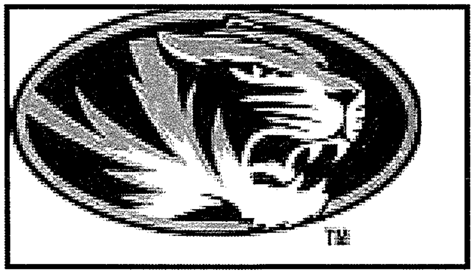
## 2. Nebraska



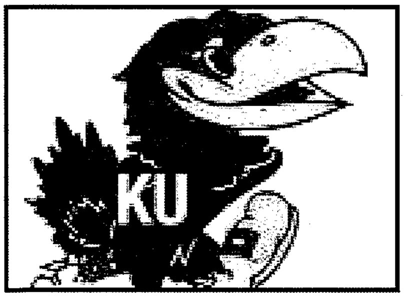
## 3. Colorado



## 4. Missouri



## 5. Kansas



# HCBS DD Waiver

1. Oklahoma $47,700 per person per year

2. Nebraska $44,500 per person per year

3. Colorado $40,200 per person per year

4. Missouri $36,700 per person per year

**5. Kansas $32,500 per person per year**

# Developmental Disabilities Services Task Force

## Report to the Legislature

March 2004

16-9

# Developmental Disabilities Services Task Force
## Report to the Legislature – Executive Summary

**Conclusion**: State law and policy must change to ensure that high quality, comprehensive, and sustainable community based services are available and accessible to all Kansans who seek them. Doing this will increase confidence in the current community based system that serves Kansans with developmental disabilities. These changes must occur concurrent to any and all policy discussions regarding closure, consolidation or privatization of state developmental disability facilities.

The Developmental Disabilities Services Task Force, whose membership is composed of five parents of people with developmental disabilities, two professional advocates, and seven community service provider representatives, was convened by SRS in response to a request from the Special Committee on Appropriations/Ways and Means. This report provides the results of the Task Force study of options for alternative usage of state developmental disabilities facilities, as requested. The report then goes beyond that to recommend a vision-based assessment of those issues, which can only be done in the context of a renewed strategic plan that supports a fully integrated and viable service system for Kansans with developmental disabilities.

The options for consolidation or privatization of existing state developmental disability facilities should not be pursued. They would create negative outcomes for people receiving services and are contrary to longstanding values guiding the system of services for Kansans with developmental disabilities. The option for closure of an existing state facility, or some version of that option, should only be considered as part of systemwide planning. Likewise, the impact of pending legislation related to the community service system should be included in such planning.

Kansas must take affirmative steps to build on past compelling successes and to restore confidence in a sustainable community based service system. Strategies for success must be built into a systemwide, multi-year plan and must include specific measures to achieve these goals:

- ✓ waiting lists are eliminated
- ✓ high quality, comprehensive community based services are readily available
- ✓ funding is sufficient for adequate livable wages to direct service staff
- ✓ medical care is available for people in the community
- ✓ adults have dental coverage
- ✓ funding keeps pace with the rising cost of doing business
- ✓ funding disparities between institutional and community services are eliminated
- ✓ funding for community based services is stable and all state funds currently used for developmental disability services continue to be used for those services
- ✓ effective transition mechanisms are available for anyone moving into a more independent service setting
- ✓ additional system considerations are identified in the report.

Because of the intensity of the charge and the relative shortness of time, the Task Force focused on the state developmental disability facilities and their context in the overall service system for Kansans with developmental disabilities. However, recommendations for future action should include the private ICFs/MR.

# Developmental Disabilities Services Task Force

## Report to the Legislature

### Table of Contents

Attachments:

#1: Summary of Task Force's Review of SRS/Health Care Policy-Developed Options for Alternative Usage of State Developmental Disability Facilities

#2: Successes on the Journey – Ten Years of Progress

#3: Task Force Charter

#4: Informing Documents

# Developmental Disabilities Services Task Force

## Report to the Legislature

March 2004

## I. Primary Recommendations

Based on the positive experiences of Kansas' developmental disability service system and the review of experiences in other states, the Task Force recommends Kansas take affirmative steps to build on our successes. The Task Force recommends stakeholders develop a renewed systemwide strategic plan and present it to key legislative committees for consideration. This plan must include specific, multi-year strategies to restore confidence in community based services, and to support the success of a fully integrated and viable service system. The Task Force further recommends state law and policy change to ensure that high quality, comprehensive, and sustainable community based services are available and accessible to all Kansans with a developmental disability who seek them.

**Build on Successes** - Kansas must take affirmative steps to build on our successes by developing a renewed, systemwide multi-year strategic plan. This plan will restore confidence in Kansans with developmental disabilities, their families, friends, advocates, service providers, and legislators. To fully realize the state policy included in the 1995 Developmental Disabilities Reform Act, changes must be made to ensure that high quality, comprehensive, and sustainable community based services are available and accessible to all Kansans with a developmental disability who seek them.

**Involve Stakeholders** - The strategic plan, as with past successful plans adopted by key legislative committees, must be developed by stakeholders, including people with developmental disabilities, families, friends, providers, legislators, direct support staff, and state agency staff.

**Strategies for Success** - Future planning must include specific, systemwide multi-year strategies to restore confidence in community based services, and to support the success of a fully integrated and viable service system. This must include:

- Modifying state law and policy to eliminate waiting lists.
- Changing state law and policy to ensure that high quality and comprehensive community based services are available and accessible to all Kansans who seek them.
- Sufficient funding that results in adequate livable wages to direct service staff providing services in the community.
- Ensuring access to adequate medical care for people receiving community based services.
- Providing dental coverage for adults receiving community based services.

- Creating a funding system that keeps pace with the rising cost of doing business and eliminates the disparity between institutional and community based services.
- Committing to stable funding for community based services, including at a minimum that all state general funds currently used for developmental disability services continue to be used for those services.
- Identifying effective transition mechanisms including sufficient start-up funding and transition staffing for any move from institutional to community based services or for someone moving into a more independent service setting.

**Conclusion**: State law and policy must change to ensure that high quality, comprehensive, and sustainable community based services are available and accessible to all Kansans who seek them. Doing this will increase confidence in the current community based system that serves Kansans with developmental disabilities. These changes must occur concurrent to any and all policy discussions regarding closure, consolidation or privatization of state developmental disability facilities.

## II. Synopsis Of Our Work

The Developmental Disabilities Services Task Force (Task Force) was convened by the department of Social and Rehabilitation Services (SRS) in response to this charge from the Special Committee on Appropriations/Ways and Means: "The Committee also recommends that the Department of Social and Rehabilitation Services 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 Task Force's charter and membership are included in Attachment #3. Membership includes five parents of people with developmental disabilities – two of whom have children living in state developmental disability facilities, two professional advocates, and seven community service provider representatives – four of whom are also parents of people with developmental disabilities. The Task Force met weekly on February 4, 11, 18, 25 and March 3, 2004. An overview of the Task Force's work includes:

On February 4th, members acclimated to each other's experience and perspective, became familiar with their charter and related background information, and heard substantive presentations from:

- Gary Ingenthron, Kansas Department on Aging, who shared the historical and current use of ICFs/MR in Kansas, both private and public. Mr. Ingenthron also explained the key licensing and Medicaid certification criteria for ICFs/MR.

- Gary Daniels, Superintendent of Parsons State Hospital & Training Center, who shared a presentation about the services provided, people receiving services, staffing, program and physical needs, and fiscal resources of that facility.
- Leon Owens, Superintendent of Kansas Neurological Institute, who shared a presentation on the services provided, people receiving services, staffing, program and physical needs, and fiscal resources of that facility.

On February 11th, members heard and received extensive information regarding national trends and federal financial participation guidelines from Robin Cooper, Director of Technical Assistance for the National Association of State Directors of Developmental Disability Services. The Task Force also had the opportunity to ask questions about the information presented, as well as potential impacts on Kansas' service system of a variety of service issues.

In preparation for its February 18th meeting, the Task Force instructed a sub-group of its members and SRS staff to develop specific cost models to consider various options for usage of the state developmental disability facilities, as well as comparative information about several service indicators across the service settings in Kansas. At that meeting, the Task Force reviewed and discussed the information that had been developed, and then had extensive discussion to start shaping their recommendations and report back to the Legislature.

On February 25th, the Task Force began writing their report, including their observations and conclusions about the options for utilization of the state developmental disability facilities and their core recommendations for moving forward.

On March 3rd, the Task Force finalized their report.

Because of the intensity of the charge and the relative shortness of time, the Task Force focused on the state developmental disability facilities and their context in the overall service system for Kansans with developmental disabilities. However, recommendations for future action should include the private ICFs/MR. Throughout the process, the Task Force received and reviewed documents and materials, listed in Attachment #4.

The Task Force appreciated the opportunity to respond to their charge, and hopes that their work and recommendations can be used as guidance for renewed, comprehensive strategic planning to move Kansas toward its desired future for services to Kansans with developmental disabilities. Task Force members are ready and willing to assist in that ongoing process, which will necessarily require substantial additional time and expanded stakeholder involvement.

## III. Answering The Questions: Review of Options for Alternative Usage of State Developmental Disability Facilities

As part of fulfilling its charter, the Task Force considered the potential impacts of several options for alternative usage of state developmental disability facilities, which it understands have been

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discussed both formally and informally. The Task Force recognizes that some of these options could be combined to create other new hybrid options. But, for clarity, it studied the impacts of each option separately. Due to time limits, the Task Force did not study the transition and transaction costs of any of these options. Transition and transaction costs are difficult to quantify and are dependent on many variables not within the Task Force's control, such as any costs of remodeling facilities or providing benefits to state staff during a transition to privatization or a facility closure.

The four options that were examined are summarized with core supporting data in "Attachment #1" to this report. The Task Force's concluding observations and recommendations are:

- **Option 1:** Close one state developmental disability facility and place all of the persons living in that facility in community based services funded by the developmental disability waiver.

  - **Observations:** The people of Kansas know how to close a state developmental disability facility. We know how to identify people who want to make that transition; we know how to meet their needs in the community; and we know how to honor the choices of people who are not prepared to make that transition. We have done that successfully, and the people participating in that process have experienced very positive outcomes.

    The Task Force notes this option must respect that funding levels shall directly go to community services, without perpetuating a disparity in services.

    "There can no longer be any serious doubt that community services are more cost effective than institutional systems. The reasons for this are well understood. Staff salaries and benefits are at the heart of the difference in costs." ("Deinstitutionalization of People with Mental Retardation and Developmental Disabilities in the United States: Was This Good Social Policy?", James W. Conroy, January 2004, p. 33.)

    ☐ **Recommendation**: The Task Force recommends that this option, or some version of it, be considered as part of the updated, comprehensive strategic planning process and strategies identified in this report.

- **Option 2:** Privatize one state developmental disability facility, or a portion of one, allowing it to keep its ICF/MR Medicaid certification, and reimburse the facility using private ICF/MR reimbursement methodologies.

  - **Observations:** The Task Force notes that this option would have significant negative impacts on the lives of people served in this facility, caused by the likely reduction in direct care staffing ratios and wages by between 29 and 50 percent.

    In addition, the Task Force observes that Kansas has a longstanding policy, since 1991, of downsizing and/or closing large private ICFs/MR. Privatizing a state developmental

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disability facility would be counter to this established policy. Finally, Robin Cooper, Director of Technical Assistance for the National Association of State Directors of Developmental Disabilities Services, indicated it would be very unlikely that a private ICF/MR provider would be willing to take over operations of such a facility, in the absence of additional, costly incentives.

☐ **Recommendation**: The Task Force does not recommend this option due to the negative impacts it would have on people being served, caused by the significant likely reductions in staff ratios and staff wages.

- **Option 3:** Consolidate the two state developmental disability facilities into one site.

  - **Observations:** The Task Force notes this option would have significant negative impacts on the lives of people served in these settings. The number of people living in each building would double and programming would change from an individualized to a group model. The positive changes in the quality of life that have resulted from the lower numbers at each facility would be seriously compromised. Medicaid certification would potentially be jeopardized as it was in the past when the facilities were at full capacity. This option is the least appealing for the people being served at the two facilities.

  ☐ Recommendation: The Task Force does not recommend this option due to the negative impacts it would have on people being served in the facilities, resulting from increased crowding and lower staffing ratios.

- **Option 4:** Privatize one state one state developmental disability facility and fund its private operation using the developmental disability waiver.

  - **Observations:** Robin Cooper reported to the Task Force that this option would not be approved by the Center for Medicare and Medicaid Services (CMS) for federal financial participation. The Task Force reviewed CMS documents provided by Ms. Cooper that confirmed her report. Also, the Task Force observes that this option is not aligned with the longstanding values guiding developmental disability services in Kansas.

  ☐ **Recommendation**: The Task Force recommends this option not be pursued further, because all evidence shows it will not be acceptable to the Centers for Medicare and Medicaid Services so significant federal funding could be lost.

## IV. Moving Forward: Guiding Considerations & Additional Recommendations

Kansas continues on the journey started in 1991 with the Legislature adopting the strategic planning document proposed by system stakeholders, entitled "Supporting Kansans With Developmental Disabilities." The direction of the journey was reviewed in January 2003 by the report "Mapping the Future: Exploring Possibilities."

The Task Force reaffirms the core values and principles of these plans are still relevant including:

- Kansans with developmental disabilities must have the opportunity to be included and integrated in the life of their community.
- A comprehensive array of support and direct services must be developed in Kansas which provides the greatest degree of integrated service options for people with developmental disabilities.
- The system of services for Kansans with developmental disabilities must be flexible and based on individual needs. Those services must be available:
  - at a time and place which does not force segregation or stigmatize individuals,
  - in a way which provides diverse service options,
  - in the least restrictive and most integrated service setting to meet individual needs,
  - which are safe, healthy and consistently meet the person's needs,
  - with opportunities to make choices about important and personal life issues,
  - based upon individualized service planning,
  - honoring the individual rights of each person,
  - by treating each person with equity, fairness and respect, and
  - provided in a cost effective manner.

In 1995, Kansas passed the Developmental Disabilities Reform Act. That act, at K.S.A. 39-1802, established that: "It is the policy of this state to assist persons who have a developmental disability to have:

(a) Services and supports which allow persons opportunities of choice to increase their independence and productivity and integration and inclusion into the community;
(b) access to a range of services and supports appropriate to such persons; and
(c) the same dignity and respect as persons who do not have a developmental disability."

Pertinent to this discussion, the DD Reform Act also provides that: "For persons moving from institutions into the community, [establish a system that] directs funding to follow in an amount not less than that which is required to reimburse community service providers for services as set forth in such person's plan for transfer from the institution to community services including expenses of relocation and initiation of services."

The combined efforts of legislators, people with developmental disabilities, their families and friends, community service providers, public and private ICF/MR providers, disability advocates and state agency staff have resulted in much progress. However, it is now time to look to the future and refocus on our goals. This must be done by developing a new, systemwide strategic plan that is presented to key legislative committees for consideration and possible adoption, and use as guidance for future strategic and funding decisions.

The Task Force reviewed efforts of other states attempting to achieve similar goals. Experience in other states demonstrates that any significant change in the array of services, without appropriate systemwide strategic planning and preparation, results in cumbersome and costly litigation, increased service costs, and failure of services for people with developmental disabilities and their families.

Task Force Recommendations

Based on the positive experiences of Kansas in the past, and the review of experiences in other states, the Task Force recommends:

1. Kansas must take affirmative steps to build on our successes and fully realize the state policy included in the Developmental Disabilities Reform Act. This includes:
   - developing a renewed, systemwide multi-year strategic plan.
   - restoring confidence in Kansans with developmental disabilities, their families, friends, advocates, service providers and legislators.
   - making changes to ensure that high quality, comprehensive, and sustainable community based services are available and accessible to all Kansans with a developmental disability who seek them.

2. The strategic plan, as with past successful plans adopted by key legislative committees, must be developed by key stakeholders, including:
   - people with developmental disabilities
   - families, friends and advocates of people with developmental disabilities
   - providers and administrators of community based and ICF/MR services
   - direct support staff
   - legislators
   - state agency staff, including state developmental disability facility representatives.

3. Future plans include specific, multi-year strategies to restore confidence in community based services, and to support the success of a fully integrated and viable service system. This must include:
   - modifying state law and policy to eliminate waiting lists.
   - changing state law and policy to ensure that high quality and comprehensive community based services are available and accessible to all Kansans who seek them.
   - sufficient funding that results in adequate livable wages to direct service staff providing services in the community.
   - ensuring access to adequate medical care for people receiving community based services.
   - providing dental coverage for adults receiving community based services.
   - creating a funding system that keeps pace with the rising cost of doing business and reduces the disparity between institutional and community based services.
   - committing to stable funding for community based services, including at a minimum that all state general funds currently used for developmental disability services continue to be used for those services.

- identifying effective transition mechanisms including sufficient start-up funding and transition staffing for any move from institutional to community based services or for someone moving into a more independent service setting.

4. In addition, the Task Force recommends the following considerations be included in the strategic planning process:
   - the entire array of services available for Kansans with developmental disabilities should be addressed.
   - the role of state developmental disability facilities and private ICFs/MR in that array of services should be identified, including ways to ensure integration and unity of service values, with active cooperation to support and be responsive to people moving across settings.
   - effective ways to ensure a viable and accessible "safety net" of services for people in crisis or urgent situations that their community does not have the capacity to then address.
   - review of services available to children and adults living with their families to ensure that services in those settings are flexible, adequately resourced, accountable to the person, the family unit and service system standards.
   - strategies to fully involve people and their family and friends in service planning and delivery.
   - the updated strategic plan should be presented to key legislative committees for consideration and possible adoption, to provide a framework for implementation of the multi-year strategies.
   - the Task Force also recommends that the impact of legislation related to the community service system be included as part of this systemwide strategic planning update.

**Conclusion**: State law and policy must change to ensure that high quality, comprehensive, and sustainable community based services are available and accessible to all Kansans who seek them. Doing this will increase confidence in the current community based system that serves Kansans with developmental disabilities. These changes must occur concurrent to any and all policy discussions regarding closure, consolidation or privatization of state developmental disability facilities.

# Developmental Disabilities Services Task Force

ATTACHMENT #1

## *Summary of Task Force's Review of SRS/Health Care Policy-Developed Options For Alternative Usage of State Developmental Disability Facilities*

Note: Due to time constraints, this review of options focuses on data relative to KNI only. A similar review of PSH&TC data must be done as part of further assessment of options in the recommended strategic planning process

**Option 1: Close one state developmental disability facility and place all of the persons living in that facility in community based services funded by the developmental disability waiver.**

**Recommendation:** The Task Force recommends that this option, or some version of it, be considered as part of the updated, comprehensive strategic planning process and strategies identified in its report.

**Impact:** The Home and Community Based Services Waiver for Persons with Developmental Disabilities (DD waiver) provides Medicaid funding for direct services provided to persons with DD living in community settings that are not certified as ICFs/MR. The DD waiver funds direct care staff, oversight, supervision, ancillary costs, and general administration. The DD waiver does not fund room and board, health care, or transportation.

Persons leaving state developmental disability facilities would require a full range of DD waiver day and residential services. Reimbursement for DD waiver day and residential services are based on tiered rates. Reimbursement for persons with relatively more severe disabilities is higher than reimbursement for persons with relatively less severe disabilities as measured by a standardized screening instrument. Also, tiered rates vary based on other factors. A reimbursement system called Special Tiers, originally designed to fund persons leaving institutions, is also available when the cost of serving a person exceeds ordinarily established tiers. The system of Special Tiers also addresses specific funding requirements contained in the DD Reform Act. The impact of placing all persons from the state developmental disability facilities was reviewed using both Special Tiers and ordinarily established tiers.

Other DD waiver funded services are also available. Most specifically a service called "Wellness Monitoring" was assumed to be needed by all persons. Finally, the Centers for Medicare and Medicaid requires that every person whose services are funded by a home and community based services waiver must have access to case management services. This too was assumed for all persons. This analysis was prepared relative to KNI, and a similar one for PSH&TC must be done as part of further assessment of options in the recommended strategic planning process.

*Kansas Neurological Institute*

The Task Force identified the following impacts of moving everyone from KNI to community based services funded by the DD waiver using Special Reimbursement Tier rates for every person, providing wellness monitoring for every person, and assuming every person receives case management.

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- The direct care staff salaries would be reduced by approximately $3.66.
- The total number of direct care staff would be increased by about 12.
- State spending on persons living at KNI of approximately $8.7 million all funds. ($3.4 million state general funds) must be shifted to other DD services.
- This estimated decrease in spending assumes that federal SSI benefits (individually paid to people with disabilities living in non-institutional settings) would be adequate to fund each person's room, board, transportation and potentially non-covered dental expenses.
- In this option, it is assumed that health care costs for people living in the community will be paid primarily by Medicaid. The issue of health care does not impact this estimated decrease in spending, since those costs were removed prior to calculating the fiscal impact.
- The Task Force observes the difficulty in finding physicians readily available to serve persons using Medicaid, especially those persons with severe and multiple disabilities. In addition, the Task Force notes that dental services for adults are not covered by Medicaid.

Likewise, the Task Force identified the following impacts of moving everyone from KNI to community based services funded by the DD waiver using ordinarily established reimbursement tier rates for every person, providing wellness monitoring for every person, and assuming every person receives case management.

- The direct care staff salaries would be reduced by approximately $3.66.
- The total number of direct care staff would be reduced by approximately 100.
- State spending on persons living at KNI of approximately $12.5 million all funds. ($5 million state general funds) must be shifted to other DD services.
- The other service impacts related to room, board, transportation, medical care, and dental care apply to this option as well.

**Option 2: Privatize one state developmental disability facility, or a portion of one, allowing it to keep its ICF/MR Medicaid certification, and reimburse the facility using private ICF/MR reimbursement methodologies**

**Recommendation:** The Task Force does not recommend this option due to the negative impacts it would have on people being served, caused by the significant likely reductions in staff ratios and staff wages.

**Impact:** The Task Force was informed by state surveyors that private ICFs/MR are certified in much the same fashion as state developmental disability facilities. Their program service delivery and the quality of care they are required to provide are all based on the same federal Medicaid standards. They are also surveyed by the same state agency staff.

Private ICFs/MR are, however, reimbursed differently. State developmental disability facilities are reimbursed prospectively based on actual expenditures. Private ICFs/MR are reimbursed based on retrospective cost reports subject to cost center limits for administrative costs and habilitation (direct service) costs. These cost center limits vary based on the facility size and the relative level of severity of the needs of persons living in the facility. To determine the potential impact of this option, the current cost center limits listed below were applied to the state developmental disability facilities.

| Facility Size | Administrative Per Diem Limit | Habilitation Per Diem Limit |
|---|---|---|
| Large +16 Bed | $10.00 | $120.00 |
| Medium 10 to 16 Bed | $23.00 | $148.00 |
| Small 4 to 9 Bed | $28.00 | $191.00 |

The Task Force identified the following impacts of applying these cost center limits to Kansas Neurological Institute's FY 2005 budgeted expenses based on the Governor's Budget Recommendation.

*Impact on KNI*

*Budgeted Resources*
KNI has sufficient staff to provide a 2.0 to 1 total, overall direct care staff to client ratio. This ratio would indicate that, on average, there is one staff on duty to support every 2.4 clients throughout the day. (The staff included in this ratio are: Mental Retardation Specialists, Mental Retardation Technicians I and II, and Client Training Supervisors.) The average hourly cost, including benefits, for these staff is $16.53 per hour.

*Impact of Cost Center Limits*
The Task Force identified the following impacts of privatizing KNI, reimbursing it using current private ICF/MR rate setting rules. These impacts vary based on which limits are applied. KNI currently qualifies as a large bed ICF/MR. But the rules could be rewritten to allow KNI to qualify as a medium or small bed facility, or the use of the facility could be modified in some options considered. For example, part of the facility could remain and operate as a small or medium bed ICF/MR, while part of it could be used for other purposes. Therefore, the impacts of the cost center limits of all three facility sizes are included:

- Impact of Large Bed Cost Center Limits
  - The total, overall direct care staff to client ratio would drop 50%, to less than 1 to 1 (one staff on duty to support every 4.8 clients).
  - Other staff, including nursing staff, would also need to be similarly reduced. Overall approximately 240 full time equivalent staff would need to be reduced.
  - The average hourly cost, including benefits, paid for direct care staff would fall 50%, to about $8.26 per hour.
  - State spending on KNI of approximately $9.7 million all funds ($3.8 million state general funds) must be shifted to other DD services.

- Impact of Medium Bed Cost Center Limits
  - The total, overall direct care staff to client ratio would drop 41%, to less than 1.2 to 1 (one staff on duty to support every 4 clients).
  - Other staff, including nursing staff, would also need to be similarly reduced. Overall approximately 183 full time equivalent staff would need to be reduced.
  - The average hourly cost, including benefits, paid for direct care staff would fall 41%, to $9.75 per hour.

- State spending on KNI of approximately $8 million all funds ($3.2 million state general funds) must be shifted to other DD services.

- Impact of Small Bed Cost Center Limits
  - The direct care staff to client ratio would drop 29%, to about 1.4 to 1 (one staff on duty to support every 3.4 clients).
  - Other staff, including nursing staff, would also need to be similarly reduced. Overall approximately 130 full time equivalent staff would need to be reduced.
  - The average hourly cost, including benefits, paid for direct care staff would fall 29%, to $11.73 per hour.
  - State spending on KNI of approximately $5.4 million all funds ($2.1 million state general funds) must be shifted to other DD services.

**Option 3: Consolidate the two state developmental disability facilities into one site.**

**Recommendation:** The Task Force does not recommend this option due to the negative impacts it would have on people being served in the facilities, resulting from increased crowding and lower staffing ratios.

**Impact:** The Task Force understands it has been observed that each of the state developmental disability facilities could potentially serve all persons currently residing in these facilities. Therefore, the Task Force has identified the following impacts of consolidating the two state developmental disability facilities into one site.

- The number of persons living in each residential living unit would nearly double.
- Whichever facility is chosen to remain open would have to be extensively renovated and remodeled.
- The estimate assumes the direct care staff to client ratio would drop from an average of 1.53 to 1 to 1.37 to one.
- The estimate assumes 137 full time equivalent staff would be reduced.
- The amount of funds available for shifting to other DD services, from consolidating the two state developmental disability facilities to one site, given the assumptions listed above, is approximately $5.2 million all funds ($2.2 million state general funds)

**Option 4: Privatize one state developmental disability facility and fund its private operation using the developmental disability waiver.**

**Recommendation:** The Task Force recommends this option not be pursued further, because all evidence shows it will not be acceptable to the Centers for Medicare and Medicaid Services so significant federal funding could be lost.

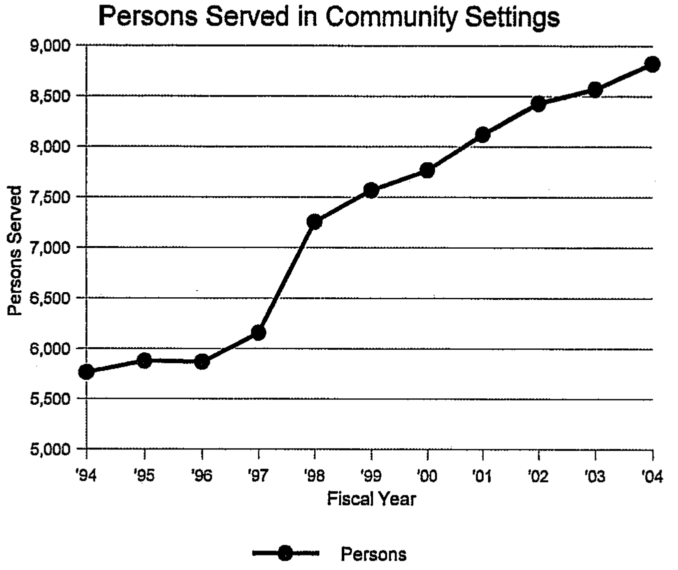
**Finding:** The Task Force understands there has been some discussion regarding potentially privatizing one of the state developmental disability facilities and funding its continuing operation using the DD waiver. The Task Force consulted with a national expert, Robin Cooper from the National Association of State Directors of Developmental Disability Services. Ms. Cooper reported that the Centers on Medicare and Medicaid Services (CMS) would not allow the use of DD waiver funds for the payment of services in an institutional setting. The Task Force confirmed this report with the review of CMS documents.

# Developmental Disabilities Services Task Force

Attachment #2

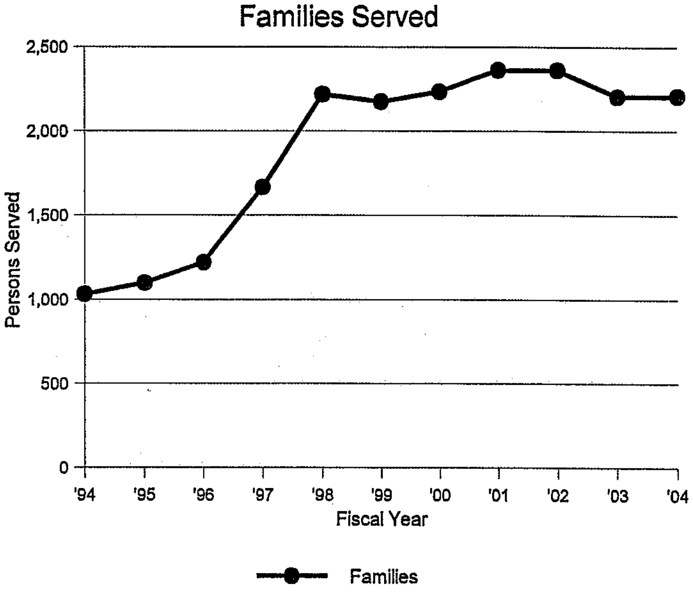
***Successes on the Journey -- Ten Years of Progress***

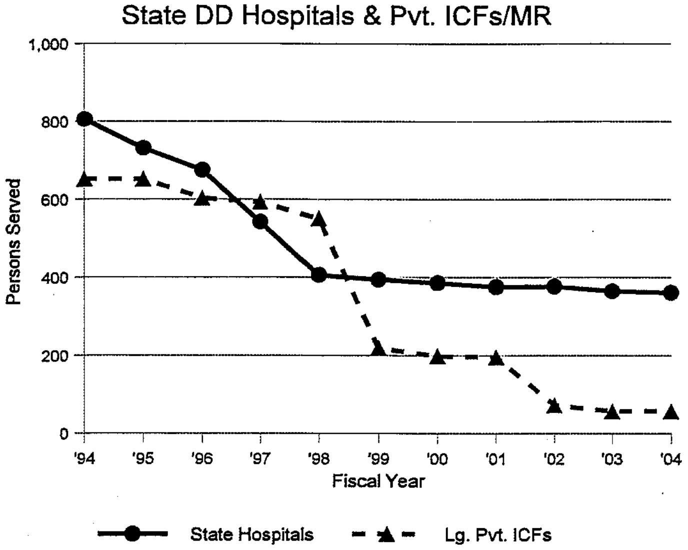
In the last 10 years, with the support of the Governors and Legislature, much progress was made in increasing the effectiveness, efficiency, and accessibility of community based developmental disability services. The progress in these areas shows what is possible when there is an agreed upon public policy and strategic multi-year plan that are used as the bases for making critical decisions related to the developmental disability service system.



The number of persons served in the community increased significantly due to increased use of federal Medicaid funds and increased appropriations to address community waiting lists.

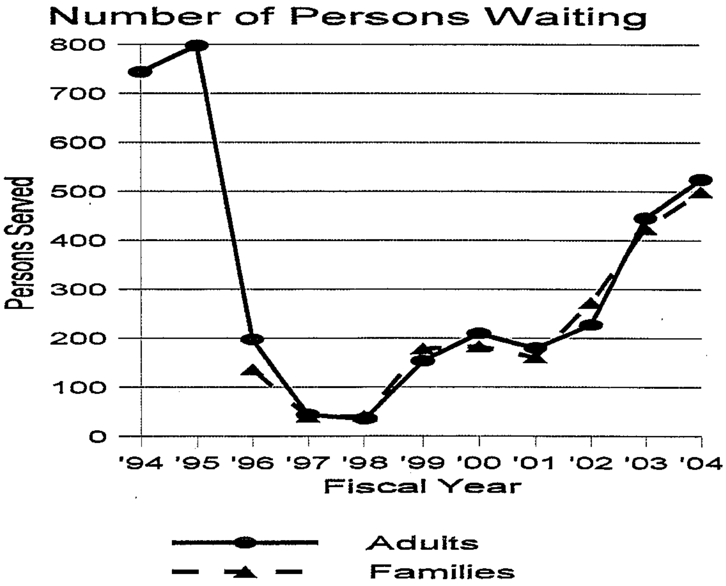
The number of families with children who are DD receiving services has increased significantly. Initially the increase was due to state funds provided for direct family subsidy. More recently, additional families have been provided in-home family support funded by the DD Waiver.



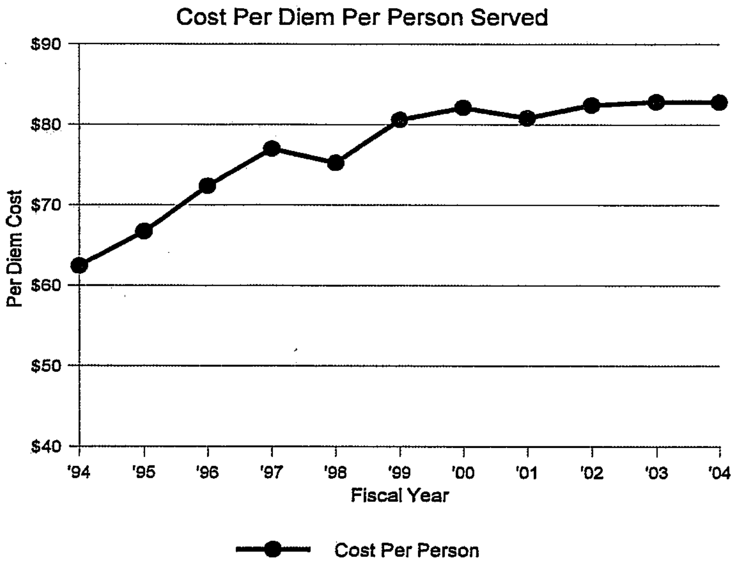


The number of persons served in state developmental disability facilities and large private ICFs/MR has fallen significantly. Families interested in moving their family member to a community setting, have done so through the principles used in Community Integration Project. Most private facilities closed when owners decided to leave the business or were forced out by poor survey results.

The number of persons waiting for services dramatically declined as more federal Medicaid funds were drawn down and increased appropriations were provided to serve more persons.



Quality enhancement processes were developed that examine the lifestyle outcomes of each person and local quality assurance process have been adopted that involve persons with developmental disabilities, their family, and friends.



Services have been provided in a cost effective manner. Funds were invested to improve services by raising the amount paid per person through FY 1999. Any subsequent increases have been relatively modest. (Note: These amounts do not include targeted case management.)

# Developmental Disabilities Services Task Force
## Attachment #3
## *Charter*

**Legislative Charge:** The Special Committee on Appropriations/Ways and Means recommends that the Department of Social and Rehabilitation Services create a Task Force that includes parents with children in mental retardation facilities, developmental disability advocates, and community providers to recommend alternative usage of intermediate care facilities for persons with mental retardation (ICFs/MR) and state developmental disability institutions and report to the 2004 Legislature by March 15, 2004.

**Task Force Members:**

- *Rocky Nichols*, Executive Director, Kansas Advocacy & Protective Services [advocate]
- *Bill McGuire*, retired [parent of adult child with developmental disabilities living at KNI and guardian of three other adults with developmental disabilities living at KNI]
- *Jane Rhys*, Executive Director, Kansas Council on Developmental Disabilities [advocate]
- *Scott Shepherd*, Director, Brookside Health Staffing [parent of adult child with developmental disabilities living at PSH&TC; community service provider working with agencies in both Kansas and Missouri to meet emergency and long-term staffing needs of community based organizations that support people with disabilities]
- *Bill Brooks*, Executive Director, Cowley County Developmental Services, Inc. [CDDO; 281people served in area]
- *Dawn Merriman*, Director, Choices Network Inc. [parent of an adult child with developmental disabilities living in his own home; community service provider assisting families of children with developmental disabilities being supported in the community]
- *Mary Ann Keating*, Executive Director, TARC, Inc. [CDDO and community service provider; 695 people served in area]
- *Mark Elmore*, Executive Director, Johnson County Developmental Supports [CDDO and community service provider; 887 people served in area]
- *Colin McKinney*, Executive Director, Sedgwick County Developmental Disability Organization [CDDO; 1,289 people served in area]
- *Shari Coatney*, Director, Southeast Kansas Independent Living Resource Center [parent of two children formerly served at PSH&TC and now living with family; community service provider for people with developmental disabilities and people with physical disabilities or head injury service needs being supported in the community]

**Facilitator**: Lloyd Swartz, Civil Solutions

**Staff:** Margaret Zillinger, Leon Owens, Gary Daniels, Lizz Phelps, Rick Shults

**Task Force Resource Persons:**

- Robin Cooper, NASDDDS
- Gary Ingenthron, KDOA

**Charter:** The Task Force will develop recommendations for the Legislature regarding how the state should use, operate, and fund state DD facilities and private ICFs/MR to most effectively and efficiently meet the needs of persons with DD in Kansas.

**Process:**

- Become informed of the various ways other states meet the needs of persons with developmental disabilities and their families specifically related to use of public and private institutions.

- Become informed of pertinent information regarding the Kansas DD services including state developmental disability facilities, private ICFs/MR, and community providers – how they operate, how they are funded, who they serve, and how they meet the needs of the persons they serve and their families.

- Become informed of the variety of ways services can be provided and funded for persons with developmental disabilities living in ICFs/MR and state developmental disability facilities and their families.

- Develop possible recommendations for the Legislature regarding how the state should use and fund state DD facilities and private ICFs/MR to best meet the needs of persons with DD in Kansas. In addition to recommendations developed by the Task Force, other potential recommendations raised by legislators should be considered including:
    - ▸ Consolidating both state DD facilities into one site,
    - ▸ Privatizing KNI, or
    - ▸ Closure of one state DD facility.

- Examine the effects of issues identified in the Interim Special Committee report on the Task Force's potential recommendations. These issues include, but are not limited to:
    - ▸ Providing adequate emergency response systems,
    - ▸ Providing customer driven services,
    - ▸ Providing services that meet the needs of persons with more severe or complex needs,
    - ▸ Difficulties in recruiting, hiring, and retaining a qualified workforce,
    - ▸ Securing appropriate affordable housing,
    - ▸ Securing sufficient, appropriate transportation,
    - ▸ The role of individual and family choice,
    - ▸ Having sufficient numbers of providers in various areas of the state capable and willing to serve persons with more severe or complex needs.

- Achieve a consensus regarding specific recommendations to be made to the Legislature by March 15, 2004.

- Review and approve the final report.

- Be available to present to the Legislature and answer questions as they arise.

# Developmental Disabilities Services Task Force

## Attachment #4

## *Informing Documents*

1. Special Committee on Appropriations/Ways and Means: Consolidation or Closure of a Mental Health or Developmental Disability Institution
2. Charter for the Task Force for Developing Recommended Usage of ICFs/MR and State Developmental Disability Facilities
3. Developmental Disability Summary for December 2003
4. History of Developmental Disability Funding and Persons Served
5. State of the State in Developmental Disabilities – Excerpts
6. Governor's Budget Recommendations for KNI and PSH&TC
7. Presentations and information regarding Parsons State Hospital Facility & Training Center and Kansas Neurological Institute.
8. Deinstitutionalization of People with Mental Retardation and Developmental Disabilities in the United States: Was This Good Social Policy?
9. MR/DD Institution Policy Considerations – InterHab: The Resource Network for Persons With Disabilities.
10. State Hospital Closure Commission Report and Recommendations
11. Kansas ICFs/MR facilities 1990 through 2003
12. Are People Better Off? Outcomes of the Closure of Winfield State Hospital (Final Report of the Hospital Closure Project)
13. "Conroy Reports Controversy," Outreach, May 1996
14. Institutional and Community-Based Systems for People With Mental Retardation: A Review of the Cost Comparison Literature.
15. Reasons for Choosing an Institution for a Home, by Kittie Umscheid, co-guardian of a brother at KNI
16. FY 2004 and FY 2005 House Social Services Budget Committee Report - Developmental Disabilities Institutions
17. SRS's FY04 supplemental budget requests summary
18. Northern Virginia Regional Community Support Center description
19. CMS correspondence: 8/94; 8/03 (responding to Pennsylvania Office of Mental Retardation letter of 7/03).
20. "The Economics of Deinstitutionalization," Chapter 14 from *Costs and Outcomes of Community Services for People with Developmental Disabilities* (in press; due out Summer 2004)
21. Developmental Disabilities Reform Act, K.S.A. 39-1802, et seq.
22. "Supporting Kansans With Developmental Disabilities," original plan October 1991; updated February 1994
23. Reports: Cross-System Comparison of Key Service Issues for DD Task Force (overall indicators; range of assessed scores, intellectual assessment; mobility and health consequences; seizure issues; medication indicators; behavioral indicators); February 2004
24. Comparison of KNI Costs With Projected HCBS & TCM Costs; February 2004
25. Estimated Fiscal Impact of Combining Two State Developmental Disability Hospitals; February 2004

40
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**Introduction:**

My name is Tom Laing, Executive Director of InterHab, a statewide association of 41 community service organizations, some of which are also community developmental disability organizations (the statutorily defined gatekeepers for the state's community DD network).

I want to thank the Commission for receiving this testimony and for your diligent efforts in recent months to give thoughtful consideration to the testimony offered regarding the closure or realignment of numerous state facilities. The hearings themselves have been a great contribution to the promotion of dialog and eventually, understanding, regarding the nature of service delivery in a number of disciplines.

**As you deliberate regarding the State's institutions for persons with developmental disabilities, please keep three general issues in mind:**

1. *The potential closure or realignment of one, or both, of the state's DD facilities is intimately connected to the lives of all persons today residing in institutions, all persons served in community, all persons on the State's waiting lists, and all who will need services in the future.* Institutions are not stand-alone programs. They must instead be seen as one part of a much larger set of efforts to address the needs of all Kansans with DD.

2. *This must be a part of a larger dialog, with all policymakers, about how we can more effectively support Kansans with developmental disabilities.* As has been the case for many years, the number of persons in institutions is shrinking while the cost per-person is growing. Community service providers face State reimbursement for their work that cannot even keep pace with costs of keeping their doors open. These two issues must no longer be seen as exclusive, but instead be considered as parts of a larger puzzle that must be solved on behalf of Kansans with developmental disabilities.

3. *The State must understand the principle that dollars should be allocated in order to serve the most persons in the most appropriate ways.* You must determine whether the current use of institutional funding is the optimal allocation of resources to meet the challenge of conceiving and managing all DD service resources as part of a unified system, rather than as two separate systems for institutional and community-based care.

**Closure or realignment of the State's DD institutions can be successfully undertaken in the best interests of persons served. This has been repeatedly proven. Thousands of persons once**

Joint Committee on
Home and Community Based
Services Oversight
October 14, 2009
Attachment 17

served in

<u>institutional settings have made the transition to, and have been served appropriately in, the community.</u>

The successful transition of persons to the community from the closures of Norton and Winfield, as well as the downsizing of Parsons and KNI (which included transitions for many with challenging diagnostic profiles, and many medically-fragile persons) proves this point.

However, it must be clearly understood that some individuals have such severe medical, psychological or behavorial challenges that institutional settings provide the necessary supports to ensure their safety. These individuals can be served in community settings. Adequate funding <u>must</u> be appropriated for their care. To do less puts providers, their staff, these individuals and the communities they live in jeopardy. Any effort to close institutional resources must ensure that providers will have resources available to appropriately and safely serve these individuals.

**<u>The following considerations are paramount:</u>**

Community budgets have not kept pace with the adjustments needed to accommodate:

1. The normal increased costs of doing business and providing services, especially as it regards wages for workers, and

2. The cost of serving persons with a broader range of diagnostic profiles which require greater service expertise in the community.

**<u>Recommendations:</u>**

*Serving more persons in the community (whether from the waiting lists or from the institutions) will require a commitment to quality-based expansion of community service capacity.* In other words, allocation of new resources into the system must be balanced between serving more persons, and assuring a quality-based approach to service provision. This is true both for persons in institutions as well as persons on the waiting list. Quality is not cheap. Attracting and retaining quality staff requires a commitment to additional investments in reimbursement rates.

*Institutional downsizing must not eliminate immediate consideration of those waiting for services already.* Policymakers must make intentional steps to eliminate the waiting list for services.

*Equity is needed in how we value and address the needs and the services of persons with DD.* The State must end the perpetuation of a system in which persons with the same needs are treated differently, depending on whether they live in a State-run institution or are served in a community-based model. This same class distinction must also be ended for workers in the community.

**<u>Conclusion:</u>**

Our state institutions are remnants of a 19th century policy based on the premise that persons with disabilities would not have the capacity to be valuable citizens, and needed to be sheltered from the community.

Our society has philosophically outgrown these notions, and proven them false. Still, institutions remain open largely due to the inertia created by their decades-long presence in their communities, and the difficulties that present themselves in closing them.

Today's institutions are light years advanced from that dark and unsavory past, and those responsible for that turnaround deserve all our thanks; but the fact remains there is today no work being done in the institutions that could not be done in the community, if the resources were placed in the community.

We urge your thoughtful consideration of the track record of the state/community partnership, which has eliminated thousands of institutional beds; and base your decisions upon those considerations.

Community programs around the State, in tandem with their local governments and the State are committed to the needs of the persons served and their families irrespective of where they reside, and they will work with you, and the State and the Legislature to carry that work forward.

Thank you for your time.

Attached:

- InterHab Policy Paper on Institutional Closure
- InterHab Policy Paper on Quality Based Community Expansion

With me also today is Mary Ann Keating of TARC a service provider of long standing in Topeka, which is TARC has a strong collaborative relationship with KNI; in fact, many of our members have long standing and positive relationships with the leaders and staff of the state's institutions.

40
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October 14, 2009

TO: Joint Legislative Committee on Home and Community based Services

FR: Tom Laing, Executive Director, InterHab

RE: Assessment of current system needs

Summary view:

We appreciate the committee's recognition of the growing number of DD service needs in the community. We agree that there are certainly some enhancements that might occur with little or no significant outlays of new resources. Nevertheless, we must open our comments by noting that their remains roughly 4000+ persons on the waiting list, and reimbursement rates (that cover everything from worker wages to benefits to training to supervision) continue to lag at 20th century levels. Significant resources are needed, and it would be dishonest for us to not call out that fact whenever we have the chance to do so.

Ongoing collaborative efforts for improvements and efficiencies:

We also note, with appreciation, the work that SRS continues to do with us, and with all stakeholders, to find ways to sustain a quality system using scarcer and scarcer resources. That effort is ongoing – and has been for the life our network. That may explains in part why the community is able to operate efficiently, because we have always had to. That does not help us know, however, whether or not we can sustain a system increasingly covered by band-aid repairs when more substantial fixes are in order.

The current year's efforts are, in our view, encouraging as SRS, stakeholders, university researchers and others have been collaborating on accelerating the employment programs for persons with DD. Over the course of several years of employment funding declines, our infrastructure of employment specialists has been in decline as well. This year we are reversing that trend, and will have more to report to you on that matter next month, if you make such an opportunity possible.

Reallocation /Realignment of System Resources:

Finally, I want to call out the most significant elephant in the room when discussing budget-neutral opportunities. That is the consideration of the reallocation of current system resources, as is currently under discussion in the closure and realignment commission.

Joint Home and Community Based Services
Date: 10/14/09
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Irrespective of what decisions you make in this matter, we implore you – once and for all – to finally examine the system of services for persons with DD as <u>one</u> system within which community and institutional programs are currently offered, instead of two systems, where resources and outcomes and expectations are viewed through a different prism for one than the other.

Then examine the allocation of resources for equity and efficiency, and finally make your decisions based on this simple test – are we serving the most persons we can serve, in the most appropriate ways possible, as efficiently as possible?

If that is not the case, then your course of action should be clear enough.

**<u>We appreciate your time today, and would stand for any questions.</u>**

17-5

# 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. 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 heath 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 critically needed workers.

In short, closure discussions need to include the official recognition that "closure" is forever. So, discussions need to include plans to avert the permanent loss of system resources. 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:

*(next)*

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.

*(next)*

17-7

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 -- <u>should not be addressed using resources from the SRS budget, but through more appropriate budgets, such as the departments of Human Resources and Commerce.</u> SRS funds must not be diverted from their proper purpose, to finance the needs of the persons served.

*(revised December 15, 2003)*

## Home and Community Based Services Waiting List

| | 10/1/2009 | Omnibus 2009 | Omnibus 2008 |
|---|---|---|---|
| ***Department on Aging*** | | | |
| HCBS/FE | - | - | - |
| Senior Care Act | 269 | 215 | 146 |
| ***Deparment of Social and Rehabilitation Services*** | | | |
| HCBS/DD | | | |
| Unserved | 1,863 | 1,650 | 1,345 |
| Underserved | 985 | 1,036 | 730 |
| *Total HCBS/ DD* | *2,848* | *2,686* | *2,075* |
| HCBS/PD | 1,382 | 552 | - |
| HI/TBI | - | - | - |
| TA | - | - | - |
| Autism | 275 | 224 | 141 |

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## Attachment C

## Department of Social and Rehabilitation Services
## FY 2010 Items Covered Internally

<table>
<tr><th>Priority</th><th>Division</th><th>Description</th><th>State Funds</th><th>All Funds</th><th>FTE</th></tr>
<tr><td>1</td><td>DBHS/CSS</td><td><b>Maintain Current Policies for the Home and Community Based Services (HCBS) Waivers</b><br>Available fee funds have been shifted within SRS and the state hospitals, freeing up state funding to support projected waiver spending in FY 2010. The Legislature will need to approve the higher expenditure limitations being requested for Title XIX and the Social Welfare Fund in order for SRS to cover these expenditures internally. This is one-time funding and new revenue sources need to be identified to sustain these programs in the current form beyond FY 2010. This funding is needed to support current waiver recipients and to continue current access policies.<br>
<table>
<tr><th></th><th>State Funds</th><th>AF</th></tr>
<tr><td>PD Waiver</td><td>6,550,146</td><td>21,557,170</td></tr>
<tr><td>DD Waiver</td><td>1,732,285</td><td>5,701,119</td></tr>
<tr><td>TA Waiver</td><td>819,774</td><td>2,697,956</td></tr>
<tr><td>TBI Waiver</td><td>908,719</td><td>2,990,683</td></tr>
<tr><td><b>Total</b></td><td>10,010,924</td><td>32,946,928</td></tr>
</table>
</td><td>$10,010,924</td><td>$32,946,928</td><td></td></tr>
</table>

## Department of Social and Rehabilitation Services
## FY 2011 Items Covered Internally

| Priority | Division | Description | State Funds | All Funds | FTE |
|---|---|---|---|---|---|
| 1 | ISD/CFS | **Adoption Support**<br>State and federal statutes provide for adoption support payments to assist adoptive families in meeting the needs of children they adopt. Children served in the Adoption Support program are expected to increase 5.1 percent to 7,569 average monthly children, and the cost per child is expected to increase 4.4 percent to $368 per child. A total of $1.4 million in state funds is needed to support the caseload increase, and $1.9 million in state funds is needed to replace federal funds that won't materialize. These expenditures are being covered by various SGF savings throughout SRS and the Hospitals. This is one-time funding and new revenue sources need to be identified to sustain this program in the current form beyond FY 2011. | $3,303,660 | $2,544,495 | |

## SRS State Hospitals
## FY 2010 Items Covered Internally

| Priority | Hospital | Description | State Funds | All Funds | FTE |
|---|---|---|---|---|---|
| 1 | Hospitals | **Workers Compensation Increase**<br>The Hospitals will be using balances in their fee funds to cover increasing workers compensation costs in FY 2010. This is being covered by one-time funding. | $2,476,130 | $2,476,130 | |

## SRS State Hospitals
## FY 2011 Items Covered Internally

| Priority | Hospital | Description | State Funds | All Funds | FTE |
|---|---|---|---|---|---|
| 1 | Hospitals | **Workers Compensation Increase**<br>The Hospitals will be using balances in their fee funds to cover increasing workers compensation costs in FY 2011. This is being covered by one-time funding and new funding sources will need to be identified in future years for these expenditures. | $2,302,145 | $2,302,145 | |
| 2 | LSH | **SPTP 17-Bed Expansion**<br>The census for the Sexual Predator Treatment Program (SPTP) is currently at 182, which is 12 above the budgeted amount. This additional funding will provide a 17-bed expansion for the program. The funding available for this expansion is a result of increasing Title XIX expenditures throughout the Hospitals. This is being covered by one-time funding and new funding sources will need to be identified in future years to cover the operations of this program. | 1,402,261 | 1,402,261 | |
| **TOTAL FY 2011 HOSPITAL ITEMS COVERED INTERNALLY** | | | **$3,704,406** | **$3,704,406** | |

19-2

## Department of Social and Rehabilitation Services
## FY 2011 Enhancement Requests

| Priority | Division | Description | SGF | All Funds | FTE |
|---|---|---|---|---|---|
| 1 | DBHS/CSS | **Maintain Home and Community Based Services Physical Disabilities (PD) Waiver Services**<br>This enhancement provides funding to maintain the current level of service in FY 2011. This level of funding will support current waiver recipients and allow continuation of a rolling waiting list policy, with two people coming off the waiver for one person going on the waiver. | $3,621,250 | $10,355,897 | |
| 2 | DBHS/CSS | **Maintain Home and Community Based Services Developmental Disabilities (DD) Waiver Caseload**<br>This enhancement provides funding to maintain the current level of service in FY 2011. This level of funding will support current consumers, and allow only new consumers in crisis to access services. | 3,283,435 | 9,389,828 | |
| 3 | DBHS/CSS | **Maintain Home and Community Based Services Traumatic Brain Injured (TBI) Waiver Caseload**<br>This enhancement provides funding to maintain the current level of service in FY 2011. This level of funding will allow the program to continue to operate without a waiting list. | 1,045,782 | 2,990,683 | |
| 4 | DBHS/CSS | **Maintain Home and Community Based Services Technology Assistance (TA) Waiver Caseload**<br>This enhancement provides funding to maintain the current level of service in FY 2011. This level of funding will allow the program to continue to operate without a waiting list. | 954,050 | 2,728,352 | |
| 5 | DBHS/MH | **Restoration of Mental Health Grants**<br>This enhancement would restore the $7.0 million reduced from the Community Mental Health Center Grants in FY 2010. State grants to community mental health centers, along with state aid and county funding, fund needed community mental health services to persons who do not have the means to pay. Approximately 2,447 persons per month will not receive needed mental health treatment as a result of the CMHC grant reduction. The enhancement would restore services to this population. | 7,000,000 | 7,000,000 | |
| 6 | DBHS/CSS | **Restoration of DD Day and Residential and Family Support Grants**<br>This enhancement would restore the $6,788,174 reduced from the DD Day and Residential and Family Support Grants in FY 2010. These grant funds support persons with DD who are not eligible for DD Waiver services or who do not need the level of support provided by the waiver. It is estimated that this reduction reduced services or negatively affected 2,450 individuals and their families. The enhancement would restore services to this population. | 6,788,174 | 6,788,174 | |

19-3

## FY 2011 SRS Enhancement Requests (Cont.)

| Priority | Division | Description | SGF | All Funds | FTE |
|---|---|---|---|---|---|
| 7 | DBHS/AAPS | **Restoration of Substance Abuse Grants**<br>This enhancement would restore $2,372,403 reduced from substance abuse grants in FY 2010. The FY 2010 reduction included $2.2 million in SGF reductions and $172,403 projected revenue shortfall in the Problem Gambling and Addictions Fund, which was used to replace SGF expenditures. This reduction of available funds in the system will result in 800 fewer people being treated for substance abuse. The enhancement would restore services to this population. | 2,372,403 | 2,372,403 | |
| 8 | ISD/Regions | **Restoration of Funding for Direct Service Staff**<br>This would restore funding for 171 direct service staff. This is the number of additional vacant direct service positions in SRS regional offices between June 2007 and July 2009 as a result of insufficient funding. Additional staffing is necessary to address rising caseloads. | 5,690,654 | 8,777,765 | |
| **TOTAL FY 2011 SRS ENHANCEMENTS** | | | **$30,755,748** | **$50,403,102** | |

## SRS State Hospitals
## FY 2011 Enhancement Requests

| Priority | Hospital | Description | SGF | All Funds | FTE |
|---|---|---|---|---|---|
| 1 | LSH | **Expand Sexual Predator Treatment Program (SPTP) Transition House**<br>This enhancement would expand the Transitional House Services (THS) program to address a growing number of SPTP residents who have achieved Phase 6 or are currently progressing towards Phase 6 in the SPTP program. This facility would be a satellite operation located outside of Larned per the requirements of 2009 House Substitute for SB 91. The requested funding would serve four residents in FY 2011 and require 11.50 FTE positions. In FY 2012, it is expected that this would increase to eight residents and 17.00 FTE positions. | $483,925 | $483,925 | 11.50 |

19-4

## Department of Social and Rehabilitation Services
## Proposed FY 2011 Reduced Resources

| Priority | Division | Description | SGF | All Funds | FTE |
|---|---|---|---|---|---|
| 1 | DBHS/CSS | **Reduce Technology Assisted (TA), Traumatic Brain Injury (TBI), Physical Disability (PD), Developmental Disability (DD) Waiver, and Autism Waiver Reimbursement Rates by 3.0 Percent**<br>This proposal would reduce the reimbursement rates paid to provide services to individuals through the Home and Community Based Services (HCBS) Waivers. This reduction in rates was chosen as an alternative to removing persons from services.<br>**SGF** **AF**<br>DD Waiver (2,868,962) (8,204,067)<br>PD Waiver (1,334,271) (3,815,473)<br>TA Waiver (231,821) (662,914)<br>TBI Waiver (109,289) (312,522)<br>Autism Waiver (9,221) (26,367)<br>**Total** (4,553,564) (13,021,343) | ($4,553,564) | ($13,021,343) | |
| 2 | DBHS/CSS | **Eliminate DD Day and Residential and Family Support Grants**<br>This would reduce the DD Day and Residential and Family and Support Grants by $4,625,000. In FY 2010, $6,788,174 was reduced from this program. This additional reduction would effectively eliminate the program. This program provides support to persons with Developmental Disabilities, providing services that would not otherwise be provided through Medicaid or other funding sources. This reduction would affect approximately 2,450 individuals. | (4,625,000) | (4,625,000) | |
| 3 | ISD/RS | **Reduce Center for Independent Living Grants**<br>Centers utilize Independent Living funding to provide staff for services to consumers such as independent living skills training, peer counseling, and individual advocacy assistance, as well as information and referral and de-institutionalization supports. Each person served develops an Independent Living plan that often includes many different services provided over a period of time. This proposal would leave a remaining budget of $1.0 million AF and would result in a loss of services to an estimated 9,276 individuals. | (1,071,956) | (1,071,956) | |
| 4 | DBHS/MH | **Reduce Community Mental Health Center (CMHC) Grants**<br>This proposal would reduce CMHCs' grants funding by $7.2 million and would result in an estimated 2,500 people losing services. | (7,222,253) | (7,222,253) | |

## FY 2011 SRS Reduced Resources (Cont.)

| Priority | Division | Description | SGF | All Funds | FTE |
|---|---|---|---|---|---|
| 5 | DBHS/MH | **Reduce Family Centered System of Care**<br>This proposal would reduce the Family Centered System of Care (FCSC) program by approximately half. FCSC provides an array of needed community mental health services to children with a serious emotional disturbance and their families who have no means to pay for these services. Approximately 9,000 youth and families would lose or receive reduced services. | (2,500,000) | (2,500,000) | |
| 6 | DBHS/AAPS | **Reduce Substance Abuse Grants**<br>This proposal would reduce the amount of funding available for addiction and prevention grants by $275,000 and result in 339 fewer individuals receiving services. | (275,000) | (275,000) | |
| 7 | ISD/CFS | **Reduce Family Preservation**<br>Family Preservation Services are intensive in-home services provided through contracts with Child Welfare Case Management Providers. This proposal reduces the program budget by 2.8 percent and would result in approximately 75 fewer families referred for services. | (275,000) | (290,238) | |
| 8 | ISD/EES | **Limit General Assistance (Cash) Tier 2 to 12 Months**<br>This proposal would limit Tier 2 cases to 12 months of eligibility rather than 18 months. The current consensus estimate for the General Assistance program is 2,747 monthly adults. It is estimated that 494 adults, representing 18.0 percent of the General Assistance caseload, would lose eligibility under this reduction. In July, 2009 eligibility was reduced from 24 months to 18 months, and the grant amount was reduced to $100.00 per month. | (381,122) | (592,695) | |
| 9 | DBHS/MH | **Limit MediKan Mental Health Assistance to 12 Months**<br>This proposal would limit those unable to meet federal disability standards to 12 months of eligibility rather than 18 months. It is estimated that 190 monthly adults would lose eligibility under this reduction. In July, 2009, eligibility was reduced from 24 months to 18 months. | (820,587) | (820,587) | |
| **TOTAL FY 2011 REDUCED RESOURCES** | | | **($21,724,482)** | **($30,419,072)** | |

*Note: No Reduced Resources are reflected for the State Hospitals. Those reductions were included in the amount reduced for SRS.

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