Approved: March 8, 1995
Date

MINUTES OF THE HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES.

The meeting was called to order by Chairman Jo Ann Pottorff at 3:30 p.m. on February 8, 1995 in Room 522-S of the Capitol.

All members were present except: Susan Wagle, Excused

Committee staff present: Patricia Pierron, Legislative Research Department
Gordon Self, Revisor of Statutes
Marian F. Holeman, Committee Secretary

Conferees appearing before the committee: Patricia Pierron, Legislative Research Department
George Vega, SRS, Commissioner, MH&MRS
Ellyn Sipp, Legislative Post Audit

Others attending: See attached list

Patricia Pierron, Legislative Research Department, presented a staff briefing on developmental disabilities (Attachment 1). Of particular interest is p.p. 1-7 through 1-11 "Trends in Deinstitutionalization and Community Living for Persons with Developmental Disabilities." Michigan has a waiting list of foster families to host developmentally disabled people. Ms. Pierron can obtain additional information on Michigan procedures.

George Vega, SRS Commissioner, Division of Mental Health and Retardation Services, explained the Family Subsidy Program and later provided additional information regarding selection of families to receive the subsidy (Attachment 2).

Ellyn Sipp, Legislative Division of Post Audit, provided an overview and summary of Post Audit report of April, 1994 "Reviewing the Transfer of Mentally Retarded Patients from State Institutions to Community Living Facilities"(Attachment 3). Special note should be taken of the Conclusions and Recommendations on p.p. 26-27.

Chairman Pottorff called for a motion to introduce a committee bill. Representative Ed McKechnie moved and Representative Gerald Geringer seconded the motion to introduce to the House on Friday, February 10, a committee bill enacting the development disabilities reform act.. The motion carried.

Copies of the bill will be available Friday afternoon for those who wish to prepare testimony. Hearings will begin on Monday February 13. Hearings will also be held February 15 and February 20.

The next committee meeting will be February 13, at 3:30 p.m. in Room 522-S.

The meeting adjourned at 4:30 p.m.

HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES COMMITTEE GUEST LIST

DATE: February 8, 1995

NAME	REPRESENTING
Robert E. Iseers	The Arc of Kansas
Josie Torrez	Families Together, Inc.
Shannon Jones	Statewide Independent Living Council
Sherry C. Diel	Kansas Advocacy & Protective Services
[illegible]	KS ASSOC OF SCHOOL BDS
Dean Strahm	Apostolic Christian Home / Lakeside Terrace
Ellyn Sipp	legislative Post Audit
[illegible]	Jo. Co. M.R. Center
Nancy Staley	LEADERSHIP SUMNER COUNTY
Tom Bridges	TARC
Jacquelyn Gordon	KCDD Council Develop Disabilities
Doug Bowman	Coordinating Council
Darvin Hirsch	SRS MH/RS
George D. Vega	"
Sharon Spratt	Cottonwood, Inc.
Martha Hodgesmith	KARF
Tom Laing	KARF
Patti Shaffer	Starkey
Bill Rawlton	Starkey

HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES COMMITTEE GUEST LIST

DATE: February 8, 1995

NAME	REPRESENTING
[illegible]	Cerebral Palsy Research

SPECIAL COMMITTEE ON WAYS AND MEANS

COMMITTEE MEETINGS

The 1994 interim Special Committee on Ways and Means met on September 6 and 7, October 3 and 4, and November 21 and 22, 1994. The minutes and testimony from those meetings are on file with Legislative Administrative Services.

BACKGROUND

Mental Retardation and Developmental Disabilities

The Legislature has examined topics dealing with mental retardation and developmental disabilities during interims for the past several years. A particular focus of these interim studies has been the increasing shift from the institutional model of providing care and services to people with developmental disabilities, to a model that emphasizes home- and community-based services. Interim committees studying this issue have been increasingly supportive of the home- and community-based model of providing services: while recognizing that people with mental retardation and developmental disabilities receive, on the whole, excellent care in institutions, especially the state's three mental retardation institutions, legislators studying the issue have increasingly added their voices to the chorus of those who say that home- and community-based care is preferable, be it for clients, their families, communities, or the state as a whole.

In response to a directive from a 1992 interim committee to select a hospital for closure, the Department of Social and Rehabilitation Services (SRS) recommended, at the beginning of the 1993 Legislative Session, that Winfield State Hospital and Training Center be closed. A House Appropriations Subcommittee rejected that recommendation, selecting instead Kansas Neurological Institute (KNI) in Topeka for closure. The House Appropriations Committee agreed with that recommendation. The Senate did not discuss those recommendations during the appropriations process, and a House bill ordering the closure of KNI, though placed on general orders, was never debated.

COMMITTEE ACTIVITIES

During the 1994 interim, the Special Committee on Ways and Means studied a wide array of topics relating to mental retardation and developmental disabilities (MR/DD). Committee members heard staff reports from fiscal staff of the Kansas Legislative Research Department, the Legislative Division of Post Audit, and the Office of the Revisor of Statutes, as well as reports from the Secretary and staff of SRS, and testimony from advocates, family members, and consumers of services for the developmentally disabled.

Staff Reports

At the direction of the Committee Chairman, staff from the Legislative Research Department provided information on a variety of topics, including:

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- **Developmental Disabilities Profile of Institutional and Community Clients.** The Developmental Disabilities Profile is a five-tiered profile of characteristics which measure the disability of an individual based upon indices for adaptive behavior, maladaptive behavior, and health needs. The Committee learned that many clients with higher levels of disabilities had been successfully placed during the Community Integration Process (the program implemented by SRS, state mental retardation hospitals, and community providers in 1992 to place hospital clients into community settings), and that the Department did not consider level of disability to be an impediment to an individual's ability to live happily in a community setting. The conclusion was, in essence, reached as well by the Legislative Division of Post Audit in an audit on the community placement process that was presented to the Committee.

- **Population Trends at State Hospitals.** The following figures were presented to the Committee on the movement of clients from state hospitals into community-care settings.

FY 1994 Average Daily Census

Hospital	Budgeted Average Daily Census FY 1994	Actual Average Daily Census FY 1994	Shortfall
KNI	265	290	25
Parsons	235	233	--
Winfield	287	309	22

FY 1995 Placement Goals

Hospital	Actual Census June 30, 1994	Target Census June 30, 1995	Clients to be Placed
KNI	285	247	38
Parsons	225	227	--
Winfield	296	269	27

Information on placement of clients was also presented by the superintendents of the three state mental retardation institutions. The Committee learned that, by fiscal year 1998, the population of all three state mental retardation institutions should be equal to the population of any two of the hospitals at the present time. This could be, according to the superintendent of one of the institutions, an optimal time at which to consider the closure of one of the institutions.

- **Funding for Mental Retardation Services.** The Committee learned that $177.26 million had been spent on services for persons with developmental disabilities

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during FY 1994. Of that total, $71.8 million was for state mental retardation institutions, $35.74 million was for private Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), and the balance was for community services ($69.74 million). Approximately 7,800 people receive services in Kansas. Of those, 961 are in private ICFs/MR, and 806 are in state hospitals.

- **Closure of Institutions in Other States.** The Committee heard a report on the closure of institutions in Michigan and Vermont. The Committee learned that the conundrums faced by those states in placing clients with MR/DD were very similar to those faced by Kansas, as were the procedures used for placing clients.

In addition to reports on these matters, the Committee received information from staff on the level of funding for MR/DD services through community mill levies, a report on the practices of Community Mental Retardation Centers' governing boards, and a review of statutes and regulations relating to MR/DD.

Other Testimony

In addition to information presented by staff, the Committee heard information from the Secretary and staff of SRS, advocates for MR/DD services, and consumers of MR/DD services and their families. Some of the topics addressed included:

- **Quality Assurance for MR/DD Services.** The Committee learned that, currently, SRS is implementing a quality assurance program using departmental employees. Twelve quality enhancement positions have been approved by the Kansas Legislature, and the positions have been filled by SRS. There are, however, advocates and providers of MR/DD services who believe that clients might be better served through a system of accreditation through a national organization specializing in the accreditation of rehabilitative facilities, the Commission on Accreditation of Rehabilitation Facilities.

- **Gatekeeping for the MR/DD Services System.** The Committee learned that in May of 1994, the Secretary of SRS had, in a Secretary's Letter, established a procedure for the entry of persons into the mental retardation services system, including the state mental retardation institutions. Under the new procedure, Community Mental Retardation Centers are the entry point for the mental retardation services system. Admissions to state mental retardation institutions are not to be considered unless the services needed by a client are not available in community settings.

- **ICFs/MR.** Members of the Committee expressed concern, along with advocates for people with mental retardation and developmental disabilities, about the large number of people residing in large-bed, for-profit ICFs/MR. Information presented to the Committee showed that there were not a lot of options open to the Legislature with regard to closing these institutions beyond those that had already been put into effect, *i.e.*, giving the Secretary of SRS the authority to refuse to enter into further contracts with large-bed, for-profit ICFs/MR. The Committee also learned, however, that SRS and some ICF/MR owners had begun a voluntary effort to downsize certain ICF/MR facilities through placement of ICF/MR clients into community settings.

- **Mental Retardation Reform**. The question of whether the state needed an MR/DD Reform Act, similar to the Mental Health Reform Act of 1987, was discussed by Committee members and conferees. Many Committee members and conferees, including the Secretary of SRS, expressed the view that a coordinated, long-term program for continuing the transformation of Kansas' system of providing MR/DD services from an institutional to a community-based system would be valuable. A task force, appointed by the Governor, and representing the views of consumers, families, service providers, and advocates was suggested as the possible point of origin for such an act. A representative task force could author an act in which consumers, families, providers, and advocates would have an investment, and which would have greater chances of long-term success than initiatives heretofore undertaken by the Legislature and SRS. 1993 H.B. 2523, along with suggested amendments to that bill, was considered as a vehicle for MR/DD Reform. The bill, however, was rejected by the Committee.

CONCLUSIONS AND RECOMMENDATIONS

The Committee reviewed the continuing transformation of Kansas' service-delivery system for people with MR/DD from an institutionally-based system to a home- and community-based system. The Committee noted with approval the success that state mental retardation institutions and community-service providers are having in creating successful placement settings for persons with MR/DD. The Committee believed that further progress towards a service-delivery model which is mostly community-based is inevitable. The Committee also considered it inevitable that the population of the state's mental retardation institutions will continue to decrease to the point at which, in the near future, it will no longer make financial sense to continue to maintain three such institutions, with their large fixed costs. Efforts by the Legislature and SRS to close an institution have failed because there has not been unity of purpose among legislators, consumers (both in institutional settings and in community environments), families (of both institutional and community clients), service providers, advocates, and townspeople of the communities that might be affected by closure. There has been reluctance to endorse wholeheartedly the community-based services model because of doubts about the adequacy, in some cases, of the care given to clients in community settings. There has continued to be fear about the possible economic impact that closure of a state mental retardation hospital would have upon a community.

The Committee believed that unity of purpose is essential if the transformation from an institutional to a community-based services model is to be successful, and if the state is going to realize the financially-necessary goal of, at some point, closing a state mental retardation hospital. We must create a system in which consumers, families, providers, advocates, and the State of Kansas have an investment and a commitment.

The Committee noted that Mental Health Reform has enjoyed much success precisely because of the investment and commitment of consumers, families, providers, advocates and the state. These people have become partners in the system, with vested interests in making sure that the system works well.

The Committee believed that the process that led to the Mental Health Reform Act of 1990 could serve as a model for a Mental Retardation and Developmental Disabilities Reform Act. In view of this, the Committee decided to request that the Governor-Elect (now Governor) appoint a task force whose task it would be to author such an act. The task force would consist of consumers of MR/DD services (both in institutions and in the community), family members of such persons, providers of MR/DD services, members of the public-at-large, and outside experts with knowledge of how a system can move successfully from an institutionally-based model to a community-based one. Members should, in the view of the Committee, be geographically representative of the state's citizenry. Support services and resources would be provided by the Department of Social and Rehabilitation Services. There would, in the Committee's view, be no legislative membership on the task force.

The Committee believed that such a task force could successfully create a system that would smooth the transformation of Kansas' MR/DD services delivery system, and provide a road map for that transition over the next several years. In the view of the Committee, the task force would:

- produce a statement of principles on which MR/DD reform would be based;
- based upon those principles, author a bill that would provide for a systematic, coordinated, and targeted approach to the reform of Kansas' MR/DD services delivery system;
- study the various funding streams for the financing of MR/DD services, including those within the budgets of SRS, the Department of Health and Environment, and the Department of Education, along with county sources of funding (the task force should consider whether there should be a minimum level of local support for MR/DD services);
- examine the current structure and governance of Community Mental Retardation Centers (CMRCs), as well as the question of whether there are services for individuals with MR/DD available outside of the CMRC structure, and if so, how CMRC and non-CMRC services might be married into a more global system that could successfully serve all individuals with MR/DD;
- examine the question of how quality assurance might best be provided; also, the question of whether there should be an ombudsman for consumers of MR/DD services;
- examine the question of whether there should be an entity (which might consist of consumers, providers, and employees from the SRS Division of Mental Health and Retardation Services) that could negotiate solutions to funding problems;

- examine the possibility of providing vouchers to consumers of MR/DD services, and allowing the consumers to choose the agencies that will provide them with services;

- examine how other states have confronted the problem of downsizing and closing large-bed, for-profit ICFs/MR; and

- discuss and recommend to the Legislature a mechanism for closing a state mental retardation institution (one possible model would be the federal commission which has recently decided upon the closure of military bases throughout the country; information with regard to this federal commission has been requested of the staff of the Kansas Legislative Research Department, and will be presented to the House Committee on Appropriations in January of 1995); also, discuss ways in which the economic impact of closure upon the host town of the institution chosen for closing might be mitigated.

In the view of the Committee, the task force would begin work as soon as possible after appointment by the Governor-Elect, and present a report on these issues, and other issues relating to mental retardation and developmental disabilities that it might choose to examine, to the 1996 Legislature.

MEMORANDUM

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February 7, 1995

To: Special Committee on Developmental Disabilities

From: Tricia Pierron, Fiscal Analyst

Re: Trends in Deinstitutionalization and Community Living for Persons with Developmental Disabilities

Introduction

Over the past 25 years, states have been seriously exploring the deinstitutionalization of persons with developmental disabilities. In nearly all 50 states, people with developmental disabilities are now living in their own homes in the community with one or two friends of their choice with support services targeted to their specific needs. Following is a profile of two states which have experienced downsizing and closure of their institutions with simultaneous development of community residential options for their citizens with developmental disabilities.

MICHIGAN

Under the purview of the Department of Mental Health, Michigan has been able to place all but 450 of its 12,000 developmentally-disabled clients into community settings. The Michigan Department of Mental Health supervises and controls both the downsizing of hospitals and the placement of clients. The state hospitals work in concert with state-controlled regional centers to place clients into residential housing who have better living opportunities in the community. The Department begins its placement process by targeting a hospital for assistance in placing clients. Targeting does not mean the hospital will be closed. Michigan feels it is important to clarify this point to avoid employee resistance and to allay parental concerns. Therefore, the Department assures that <u>all</u> clients in the system will be provided for and that agency placements will occur <u>only</u> if a better opportunity exists in the community. Michigan began with 11 hospitals and now only three remain.

Placement Steps

The placement process follows a sequence of actions beginning with the targeting of an institution. A sending team and a receiving team are established to coordinate the transition of the client from the institution into the community. Community settings are screened as client needs are identified. A match is formed and a referral is made to the hospital and regional center. If the referral match is

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accepted by the client, hospital, regional center, and family, a client specific exit plan is designed and implemented.

Family Consent

Parents' perceptions of community options are the biggest hurdles this and other states find they must overcome before successful placements of clients can be made. Parents are not as confident or sure about community providers when the possibility of community placement is first broached. They see the state and its institution as a stable entity -- something that will be around to take care of their family members even when they are gone. Thus, hospitals and regional centers focus their efforts on working at a micro-level with the clients and their relatives to explore the placement options best suited to their wishes. The regional centers and the hospitals are in frequent communication with client families, letting them know what options are available, taking them to the sites, and listening to the families' concerns. Families are also reassured that they do not have to move their family member from the institution if they do not want them to leave. Once the family preferences are identified, a placement process is set in motion, if this is the family's desire.

Placement Sites

The hospitals and regional centers are extremely careful about placement setting choices. Individuals are placed in only the safest neighborhoods and are closely monitored. As a result, there is little if no resistance to community placement from the clients and their families. As a matter of fact, the complaint the placement teams most often hear is of placement settings being more luxurious than what the client's family can provide.

Community Housing

The State of Michigan leases from private real estate investors the properties into which the clients move, while the service providers are arranged through contracts with the State. By keeping the housing needs separate from the personal service requirements, the State is allowed flexibility in maintaining the best possible service for the clients. If a service provider proves to be inadequate, the State can contract with another provider without having to disrupt the clients' lives by moving them out of their homes. As a result, the clients have more control over their lives and the parents are more accepting of the arrangements. A lease lets the State change locations at the end of the lease term, if the location no longer fits its needs. In addition, by leasing property from real estate investors rather than owning property, the State avoids tying up its capital. The State is not likely to move, however, as private real estate investors normally have their residential property in desirable neighborhoods. This system, of course, functions differently than foster family situations. The foster families own their own homes but are highly scrutinized from the outset by the Department of Mental Health. Client placements are totally voluntary and are made in only appropriate settings.

Foster Care Training

Clients living in foster homes benefit from well trained families. Agencies provide interdisciplinary training to families who have contracted to handle individuals with difficult care needs. Nurses, psychologists, experienced foster parents, and social workers are available to train foster families.

These professionals intervene and assist with client care when needed. Agency case managers develop treatment plans in cooperation with the professional teams which the families follow. The families also receive per diem funding of $35 - $40 to help defray the costs of caring for the client. The training and funding serve as positive incentives to foster families to accept a developmentally disabled person. The families feel valued as community providers when they are trained and empowered with knowledge, plus compensated for their efforts. Michigan has a waiting list of foster families who want to host developmentally disabled individuals.

Population Profile

Macomb-Oakland Regional Center, as an example, has placed 2,600 individuals into communities north of the Detroit area. It has developed more community living arrangements for people with severe disabilities than any other local service system in the country. It is currently serving 1,700 individuals. More than 60 percent of its clients have severe or profound mental retardation. One hundred fifty of its clients are independent individual apartment dwellers. They are assisted with agency support and also benefit from Medicaid waivers. Approximately 650 are in homes of six or less. They also receive Medicaid funding. These homes are referred to as Intermediate Care Facilities for the Mentally Retarded (ICFMRs). The newer homes house from two to six persons. Six hundred and fifty individuals live in these homes. One-half of these residents receive Medicaid waivers as well. Those situations housing six individuals were some of the first placements made, and because it was a high priority at the time to simply get individuals deinstitutionalized, the agencies consented to placement of six individuals to a home when the ideal is two to four to a home. Two hundred of the 1,700 clients live in foster care homes and are supported with Medicaid (for personal care needs) and federal Supplemental Security Income (SSI) benefits. Fifty of their clients stay with their birth families and receive some Medicaid funds as well.

Michigan is presently considering the idea of issuing vouchers to its clients. The vouchers would give clients a certain number of credits with which they could purchase homes or perhaps rent property. The choice would be that of the clients', increasing the amount of control and independence they would have in their lives.

The training and monetary incentives have been especially important in the successful placement of children in Michigan. The developmentally disabled child is considered a family of one for the purpose of determining SSI benefit eligibility. As such, the child is entitled to separate funding in the form of a federal entitlement for the disabled. The foster and natural family's incomes are not considered in the determination of the developmentally disabled child's eligibility for these funds. Needless to say, it is usually easier for a child to achieve this disability eligibility when only the child's assets, rather than the entire family's assets, are considered to determine eligibility. The natural family is still required to help support their developmentally disabled relative in a foster setting pursuant to the Michigan Mental Health Code. The State, however, supplements the federal Supplemental Security Income (SSI) moneys that the foster family receives, to enable them to receive $35-$40 per diem funding, if necessary. In addition, the State of Michigan will pay $6-$7/day to fund a child if the child remains with its birth family and for some reason SSI moneys are difficult to receive.

Monitoring

Monitoring is achieved through a combination of agency efforts and unannounced visits by volunteer advocate groups. The State of Michigan, for instance, organizes parent monitoring groups that visit homes and report back directly to the agency director. If any problems exist, the agency director contacts the case manager to address the problem. Parents are reimbursed for their mileage and secretarial support is available to them, as well. Case managers also make weekly visits to the homes and are in daily telephone communication with the placement sites. Agency personnel hold monthly and bimonthly meetings with case managers to keep abreast of placement activities. Agency personnel also meet every quarter with the State central office to examine macro-level system issues. Finally, Michigan officials also stressed the importance of having an effective grievance procedure in place for clients and their families that would allow them to communicate their concerns to Department personnel directly.

County Funding

In Michigan, the county where the developmentally disabled individual entered the state system is the county that pays the bills for all future client care. The bills are sent to this county and are paid to the central office. The moneys received are distributed by the central office to the counties where the clients currently live. If a county chooses not to pay for the client's bills, it may make a deal with the host county and let it receive its tax funding. The State has funding power over the counties, and if necessary, can require the county of origin to fulfill its obligation. The State has found it is less costly to house individuals in the community than to operate an entire institution, and, even if it were not, Michigan is committed to these individuals' positive integration into the community. In Michigan, county funding accounts for 10 percent of a client's needs. The state provides the remainder.

Further Placement Considerations

Michigan, as well as the other states interviewed (Massachusetts, Vermont, Minnesota, and Colorado), are able to place their medically fragile clients more easily than those with behavior problems. It takes more time to prepare the setting for the medically fragile client, but once that preparation is accomplished, placement is stable. Local health care can often provide equal, if not superior care, than state system institutions. In our own state, Winfield State Hospital and Training Center has not had one patient permanently return to the institution after placement. (Only four patients of the 91 placed have briefly returned, only to go back to their home in the community. Three of these were for behavioral problems and one was medically related. Of these four, one client returned to KNI for behavioral problems, rather than Winfield.) Clients with medical problems have benefitted from home health advances while treatment plans for clients with behavior problems are still in the developmental stage. Parsons has had numerous behavioral problem client returns to their facility. One has returned permanently and several have entered the court system.

Officials in Michigan suggest that if Kansas is considering closure of an institution, it needs to first assess what function the hospitals serve, and then determine if Kansas can replicate those services in the community. For example, if Kansas has individuals who are returning to state facilities after placement into the community, does it have personnel or community facilities that can offer respite or care that the hospitals once offered? Michigan is considering building secured 10-15 bed units for their behavioral problem clients that are presently still institutionalized. Due to Michigan housing codes which limit the number of people living in group homes, it is facing some problems with this idea.

Employees

Placement of employees has not been a great problem in Michigan. Many employees have been able to find alternate employment in correctional facilities that moved into vacated hospital facilities. Other

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employees have found employment in the private sector with nonprofit organizations providing care for clients in the community setting. The wages, however, are disparate between the state and private sector jobs which can make it difficult to find qualified employees willing to accept lower wages. Rhode Island, as another example, agreed with their state employee unions that no permanent employee of a mental retardation state institution will be involuntarily laid off or suffer a reduction in pay as a result of downsizing or closure. The main employee safeguard in Rhode Island was transfer to a state-operated community placement center.

VACATED FACILITIES

Michigan has transformed some of its vacated hospitals into office space, battered women's shelters, and correctional facilities. Other states have reported it is too expensive even to raze vacated buildings, so they board them up. Following is a list provided from research performed by the University of Minnesota indicating the uses to which other states have put their former mental retardation hospitals.

Of 89 facilities closed, 27 were put on the open real estate market, razed, or vacated with no alternative use found for the facility. Twenty facilities became prisons or juvenile detention centers. Nine were converted to educational or recreational uses, and four became health care facilities.

ATTACHMENT 1

CLOSED MENTAL RETARDATION FACILITIES -- ALTERNATE USES OF FORMER MENTAL RETARDATION FACILITIES

State	Institution	Year Built -- Became MR	Original Use	Population When Closure Announced	Year of Closure	Alternate Use
Arizona	Phoenix	1974	MR Facility	46	1988	Sale Pending: Commercial
California	De Witt	1942--1947	Army Hospital	819	1972	Placer County Recreation
	Modesto Unit	1943--1948	Army Hospital	1,394	1969	Community College
Colorado	Pueblo	1935	MI/MR Facility	163	1989	Pueblo Regional Center
	Wheatridge	1912	MR Facility	80	1994	Colorado Land Board
Connecticut	Mansfield	1906--1917	Epileptic Colony	146	1993	Corrections/U. of Connecticut
	New Haven	1964	MR Facility	56	1993	Job Corps
D.C.	Forest Haven	1925	MR Facility	1,000	1991	Public Health Infirmary
Florida	Tallahassee	1925--1967	TB Hospital	350	1983	Unoccupied: Asbestos
	Orlando	1929--1959	TB Hospital	1,000	1984	Unoccupied: Asbestos
Illinois	Bowen	1965	MR Facility	105	1982	Corrections
	Dixon	1918	MR Facility	820	1987	Corrections/New MR Facility
	Galesburg	1950--1969	Army Hospital	350	1985	Head Start/Community Programs
	Choate (Anna)	1873--1993	MI	17	1993	Closed child/Adolescent Section
Indiana	Central State	1848	MI/MR Facility	83	1994	Undetermined
Kansas	Norton	1926--1963	TB Hospital	60	1988	Corrections
Kentucky	Frankfort	1860	MR Facility	650	1972	Demolition

State	Institution	Year Built -- Became MR	Original Use	Population When Closure Announced	Year of Closure	Alternate Use
	Outwood	1922--1962	TB Hospital	80	1983	Demolition
Maine	Pineland	1908	MR Facility	265	1995	Undetermined
Maryland	Highland Health	1870--1972	General Hospital	88	1989	Division of Mental Health
	Henryton	1928--1962	TB Hospital	312	1985	Juvenile Facility
	Victor Cullen	1906--1974	TB Hospital	79	1991	Private Juvenile Facility
	Walter Carter	1978--1978	MH/MR Facility	10	1990	Mental Health
Massachusetts	Belchertown	1922	MR Facility	297	1992	Vacant
	Paul Dever	1940--1946	POW Camp	294	1994	None
Michigan	Alpine	1937--1959	TB Hospital	200	1981	Notsego County Offices
	Coldwater	1874--1939	Orphanage	113	1897	Corrections
	Fort Custer	1942--1956	Army Hospital	1,000	1972	Corrections
	Hillcrest	1905--1961	TB Hospital	350	1982	Demolition
	Muskegon	1969	MR Facility	157	1992	Vacant
	Newberry	1896--1941	MI Facility	39	1992	Vacant
	Northville	1952--1972	MI/MR Facility	180	1983	MI Facility
	Oakdale	1895	MR Facility	100	1991	Vacant
	Plymouth	1960	MR Facility	837	1984	County/State Offices
	Macomb/Oakland	1967--1970	Commercial Development	100	1989	Reverted to Commercial Development
Minnesota	Fairibault	1879	MR Facility	501	Pending	Partly Correctional
	Owatonna	1895--1947	Orphanage	250	1970	County/City/Substance Abuse

State	Institution	Year Built -- Became MR	Original Use	Population When Closure Announced	Year of Closure	Alternate Use
	Rochester	1879--1972	MI Facility	150	1982	Federal Corrections
	Moose Lake	1938--1970	Psychiatric Hospital	34	1995	Corrections
New Hampshire	Laconia	1903	MR Facility	4	1991	Corrections
New Jersey	Johnstone	1955	MR Facility	239	1992	Corrections
New Mexico	Villa Solano	1964--1967	Missile Base	82	1982	Demolition/Community Housing
	Fort Stanton	1964	Outpost/TB	145	1995	Skilled Nursing/Respite Care
New York	Adams	1912--1967	TB Hospital	180	1993	Possibly City of Buffalo Use
	Bronx	1977	MR Facility	217	1992	None
	Brooklyn	1972	MR Facility	378	2000	Substance Abuse
	Craig	1896--1935	Epileptic Hospital	120	1988	Corrections
	Fineson	1971	World's Fair	478	2000	None
	Heck	1972	MR Facility	274	2000	None
	Letchworth	1911	MR Facility	704	2000	None
	Long Island	1965	MR Facility	682	1993	None
	Manhattan	1919--1972	Warehouse	197	1992	State Offices
	Newark	1878	Custodial Asylum	325	1991	Community College
	Rome	1825--1894	Poorhouse	638	1969	Corrections
	Staten Island	1942--1952	Army Hospital	692	1967	Offices/Community College
	Sunmount	1965	TB Facility	322	2000	None
	Syracuse	1851--1972	MR Facility	409	2000	None

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State	Institution	Year Built -- Became MR	Original Use	Population When Closure Announced	Year of Closure	Alternate Use
	Wassaic	1930	?	979	2000	None
	Westchester	1932--1979	MI Facility	195	1988	MH Office
	West Seneca	1962	MR Facility	683	2000	None
	Wilton	1960	MR Facility	370	1995	No Plans
North Dakota	San Haven	1922--1973	TB Hospital	86	1978	None
Ohio	Broadview	1930--1967	TB Hospital	178	1992	City Administration/Retirement
	Cleveland	1855--1963	MI Facility	149	1988	Vacant
	Dayton	1855--1979	MI/MR Facility	52	1983	Mental Health Offices
	Orient	1898	MR Facility	800	1984	Corrections
Oklahoma	Hissom	1967	MR Facility	451	1994	Possible Corrections
Oregon	Columbia Park	1929--1963	TB Hospital	304	1977	Community College
	Eastern Oregon	1929--1963	TB Hospital	240	1984	Corrections/New MR Facility
Pennsylvania	Allentown	1974	MI/MR Facility	40	1988	MI Facility
	Clark's Summit	1974	MR Facility	40	1991	MI Facility
	Cresson	1912--1964	TB Hospital	155	1982	Corrections
	Harrisburg	1972	MI/MR Facility	60	1982	MI Facility
	Hollidaysburg	1974	MR Facility	60	1976	MI Facility
	Mercy Center	1915--1974	TB Hospital	152	1982	Vacant
	Pennhurst Center	1908	MR Facility	179	1982	Veterans' Medical Center
	Philadelphia	1983	MI/MR Facility	60	1989	MI Facility

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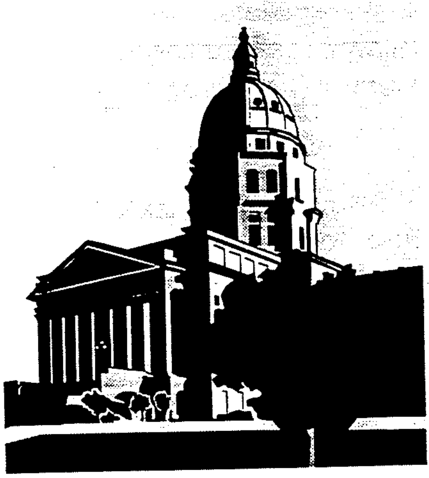
State	Institution	Year Built -- Became MR	Original Use	Population When Closure Announced	Year of Closure	Alternate Use
	Warren	1975	MI/MR Facility	50	1976	MI Facility
	Wernersville	1974	MI/MR Facility	40	1988	MI Facility
	Woodhaven	1972	MR Facility	282	1993	Temple Univ.
Rhode Island	Ladd Center	1907	MR Facility	292	1993	None
	Dix Building	1945--1982	WPA	80	1989	Corrections
Texas	Fort Worth	1976	MR Facility	339	1995	None
	Travis	1934	MR Facility	585	1999	None
Vermont	Brandon	1915	MR Facility	26	1993	For Sale
Washington	Interlake School	1946--1967	Geriatric MI	123	1995	State Offices
West Virginia	Greenbrier	1801--1974	Women's College	56	1993	Community College
	Spencer	1893	MI/MR Facility	150	1989	Possibly Corrections
	Weston	1864--1985	MI/MR Facility	99	1988	MI Facility

Kansas Legislative Research Department
February 7, 1995

SPECIAL COMMITTEE ON WAYS & MEANS



During the 1995 interim the Kansas Legislature appointed a Special Committee on Ways and Means to review the status of the state's MR/DD services. The Committee was chaired by Representative Rochelle Chronister, chairman of the House Appropriations Committee, and included influential legislators from the Senate Committee on Ways and Means and the House Appropriations Committee. The Committee met three times during the interim, and heard input from service agencies, advocacy organizations, and MR/DD Services in an effort to determine the need for mental retardation reform.

The final two day meeting of the Committee took place on November 21 and 22 resulting in the following deliberations and actions.

The Committee discussed the advisability of using old HB 2523 as the basis for placing mental retardation reform in statute and decided against that course of action at this time.

The Committee voted to request a Governor's Task Force be established by Governor-elect Graves to report to the 1996 legislature on the following:

* A review of where Kansas is and where it came from in MR/DD Services
* A quick review of what is happening elsewhere although it appears the Committee feels Kansas is doing what other leading states are doing
* Recommendations on the following key policy issues

- Consumer directed services
- The role of CMRCs particularly: governance, their apparent monopoly on service dollars, the refusal of some to adopt "zero reject policy", the waiting lists for community services, and the history of CMRCs and possibility for establishing competition through services independent of the CMRC
- Family support services
- Parent Assistance Network statewide
- Transition from Special Education
- Part H and Part B funds and how can they best be administered
- Establishing and arbitration or ombudsman process to mediate disputes between providers and SRS on individual rates
- Role of the Kansas Planning Council on Developmental Disabilities
- Role of Vocational Rehabilitation and use of 110 funds
- How to eliminate large for profit ICFs/MR
- How to assure continuous oversight of community services through the quality assurance process
- MR/DD Reform Legislation
- Recommending a process to be established to determine which hospital(s) should be closed (not name the hospital). An example given was the Closure Commission established at the federal level to nominate which military bases should be closed.

The Committee recommended the Task Force consist primarily of consumers and services agencies. Secretary Whiteman indicated MR/DD Services would provide the staffing and

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support for the Task Force. The Committee also will recommend no legislators serve on the task force. Pursuing a model similar to the Mental Health Reform Task Force was discussed, but concerns were raised about the number of providers and provider representatives initially involved in that group.

Among other areas of discussion, the conclusion appeared to be Kansas will continue to downsize mental retardation state hospitals and in the next three or four years closing of one or more may become inevitable. The Legislature's goal will be to try to deal with the economic effect on employees and the community(s).

MR/DD Services looks forward to working with all the stake-holders should Governor-elect Graves implement the recommendations of the Special Committee on Ways and Means. Kansas has made exceptional progress over the past few years with the support of consumers, parents, community agencies and the Legislature. Continued collaboration can only increase the benefit to Kansas citizens with mental retardation and other developmental disabilities.

EXECUTIVE SUMMARY

The Task Force concludes that the Department of Social and Rehabilitation Services is basically in a state of malaise with poor employee morale and no clear mission, and believes that the agency must be transformed. The following principles should guide transformation: agency employees must be involved in decision-making and empowered; the focus of the delivery system must be client-centered; and the state must exercise initiative and develop state policy priorities for social services. The Task Force also concludes that greater emphasis must be placed on preventive services, in-home and community-based services, and early intervention.

ORGANIZATIONAL STRUCTURE AND SERVICE DELIVERY

With regard to organizational structure and delivery of services, the SRS Task Force recommends:

1. that SRS explore the Total Quality Management concept as a tool to transform management of the agency, with the approach holding the promise that it is possible to deliver higher quality social services at a lower total cost to the organization;
2. that training opportunities for employees be enhanced;
3. that the agency develop a client-centered service delivery system with emphasis on strengthening field staff, coordination of service delivery, and case management;
4. that greater emphasis be placed on equipping and empowering clients to achieve self-sufficiency;
5. that the state evaluate its priorities and exercise state initiative in designing programs to meet state priorities; and
6. that the state more assertively seek waivers from federal regulations that impede the state's direction of its own social services policy and that the state communicate more assertively with federal representatives concerning federal mandates; particularly where those mandates do not complement state policy priorities

MENTAL HEALTH AND RETARDATION SERVICES

With regard to mental health and retardation services, the SRS Task Force concludes and recommends:

1. As the Mental Health Reform Act is in the first stages of implementation, the Legislature should continue to monitor implementation and receive periodic updates from the Department of Social and Rehabilitation Services regarding implementation status.
2. The State of Kansas shoud establish a policy directed towards serving individuals closest to their home communities.
3. SRS should begin planning for a reduction in the number of beds in state mental retardation institutions and report those plans to the Legislature by January, 1992.

4. The House Appropriations Committee and Senate Ways and Means Committee should review the current policy of assigning multiple subcommittees to make related budget divisions. The Task Force recommends that one subcommittee review all seven hospital budgets and the Mental Health and Retardation Services portion of the SRS budget, or, in the alternative, that the Subcommittee reviewing the mental health and retardation hospitals' budgets conduct joint meetings with the SRS Subcommittee to establish a continuity in funding recommendations for these agencies.

5. H.B. 2578, which establishes a Governor's Commission on Mental Retardation, shoud be reintroduced in its final form, and that the bill include a subsection stating that the Commission shall identify problem children with special needs and develop a master plan to address those needs; and that the charge of the Commission include advocating for long-range transition planning, and in particular encouraging vocational rehabilitation and the Department of Education to cooperate and work together.

6. A strict formula of reimbursement for ICFs/MR shoud be developed.

7. Legislation should be recommended establishing a pilot family support system in Kansas with the pilot project limited to 200 families or less, with a $3,000 annual subsidy limit per family, and that SRS report back to the Legislature on the status of the pilot program.

Medical Services

With regard to medical services, the SRS Task Force concludes that the Kansas experience with the open-ended nature of Medical Assistance expenditure is not unique, that virtually every state is experiencing the same type of out-of-control cost escalations in medical programs that Kansas has experienced, and that changes need to be made in the state's policies. Since, in the foreseeable future, the cost of medical services will increase, it is necessary to control the demand for services and establish priorities for program emphasis because acceptable options for program cuts have been exhausted. Therefore, the Task Force recommends:

1. that medical services program policy be one of emphasis on prevention and early intervention, with a focus on those services that prevent illness and disease in order to keep individuals from needing to enter the illness care system which represents the most costly component of health care;

2. that health education receive a high priority, including health education that assists the individual to accept more responsibility for his own health and teaches Medical Assistance clients the value of preventive health care and appropriate utilization of the health care system;

3. that, in the short-term, governmental resources be expended to help the greatest number of people and to prevent illness and conditions that require an extraordinary expenditure of health resources at a later time, including services under the Medical Assistance program which should be directed less to individualized high-cost acute care procedures that restrict resources that otherwise would be available for primary and preventive care;

4. that legislation be introduced to create pilot programs to deal with the issue of teen pregnancy and its associated costs and problems;

5. that legislation be introduced that places the responsibility for negotiating rates for all direct reimbursement for health care by the state with a single state agency, including health care services currently reimbursed through health benefits programs for state employees;

6. that legislation be introduced creating a board or commission based on the public utility regulatory model and assigned responsibility for establishing reasonable rates for institutional care (hospital and adult care home) services;

7. that the existing MediKan program be replaced with a new Kansas Health Benefits program under which some of the working poor and current MediKan recipients would be eligible to apply for limited health services benefits for which they would pay a monthly premium set by the Secretary of SRS as proposed by the Commission on Access to Services for the Medically Indigent and Homeless in 1990 S.B. 444;

8. that Medicaid eligibility relating to pregnant women and infants remain at the currently authorized level and that intensive targeted outreach and intensive case management services targeted to specified eligible populations be developed as proposed by the Special Committee on Public Health and Welfare under Proposal No. 31;

9. that the Legislature support the recommendation of the Special Committee on Public Health and Welfare on Proposal No. 32 to make grant funds available to enable several local health departments to operate demonstration programs to determine the feasibility of providing primary care services to the medically indigent and Medicaid clients as set out in 1991 H.B. 2019;

10. that the state's priority in long-term care continue to be the provision of long-term care services outside of institutions and in the individual's own home or a community setting and that such policy be further implemented by:

    a. the introduction of legislation mandating that any individual seeking admission to an adult care home participate in prescreening prior to admission;

    b. the introduction of legislation that creates a moratorium on reimbursement by Medicaid for any nursing facility adult care home bed built or created through conversion after a date specified in the legislation;

    c. the introduction of legislation that creates a long-term care planning commission that includes members of the public, the Legislature, and appropriate executive agencies; and

    d. direction from the Legislature to the Secretary of Social and Rehabilitation Services aggressively to seek waivers that will enable Medicaid expansion in alternate services and place emphasis on adult foster care homes as an alternative to institutional services; and

11. that the Legislature be requested to establish a broad based task force to study and to make recommendations for a system of medical procedure priorities to be utilized in allocating available Medicaid dollars.

Children and Youth Services

With regard to services for children and youth, the SRS Task Force recommends:

1. that pilot projects to study the viability of local children's authorities be undertaken in two-four judicial districts of the state;

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2. that Kansas' statutes regarding the severance of parental rights be brought into line with guidelines on this subject published by the National Conference of State Legislatures;

3. that the Department of Social and Rehabilitation Services prepare a report on options that could be taken to effect a radical improvement in child protective services, which the Task Force considers an urgent necessity;

4. that the Department of Social and Rehabilitation Services prepare outcome measurements by which the effectiveness of children's services in Kansas can be measured;

5. that a team of outside professional consultants, working in cooperation with experts from in-state universities, study the Department of Social and Rehabilitation Services and recommend changes and improvements, especially from the standpoint of changing the orientation of Kansas' social services system from reactive to preventive;

6. that the state's judicial districts be required to conduct needs assessments for children's services and to formulate long-range plans for the provision of children's services within each district; and

7. that the state conduct a needs assessment for children's services, and that it develop a long-range plan for the provision of services to children and youth; a legislative working group, would provide leadership during this needs assessment and the formulation of the State's long-range plan for children's services.

Report on Kansas
Legislative Interim Studies
to the
1992 Legislature

TASK FORCE ON SOCIAL AND REHABILITATION SERVICES

Filed With the Legislative Coordinating Council

January, 1992

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RE: PROPOSAL NO. 19 – DEPARTMENT OF SOCIAL AND REHABILITATION SERVICES

INTRODUCTION

Proposal No. 19 directed the Task Force on Social and Rehabilitation Services to:

> Study and evaluate the administrative structure and functioning of the Department of Social and Rehabilitation Services, with an emphasis on improving the cost-effectiveness of the delivery of services; review the effectiveness of the administration of programs and functions with particular focus on reducing duplication in the delivery of services, improving cooperation among agencies and administrative units, and maximizing resources through better utilization of matching funds; review rules and regulations adopted by the federal government and the Secretary of Social and Rehabilitation Services to determine whether these regulations assist or hinder in the administration of programs and functions of the Department and identify and evaluate cause of programmatic cost increases.

The Task Force was first established by the Legislative Coordinating Council for the 1990 interim. The Task Force prepared a report and recommendations to the 1991 Legislature based upon the work of four subcommittees.

For the 1991 interim period, the Task Force divided into the following four subcommittees: mental health and retardation services; financing; prevention; and medical services and long-term care. Each Subcommittee was directed by the Task Force to study and review certain topics pertaining to the Department of Social and Rehabilitation Services. The Subcommittees met each month to receive information and develop recommendations in their subject area. In some cases subcommittees visited community facilities as a part of the information gathering process. The Subcommittee on Mental Health and Retardation Services participated in a "Uniting Our Vision" conference in September dealing with the concerns of people with developmental disabilities. Several Subcommittees, along with other legislators, took part in a November conference hosted by the University of Kansas School of Social Welfare concerning investing in social services. Subcommittees made reports to the full Task Force at a December meeting. The Finance Subcommittee met subsequently in early January to modify its recommendations in response to Congressional action.

For the 1991 interim, the Task Force consists of the following 17 legislative members and seven public members:

Rep. Gary Blumenthal, Chairperson
Sen. August Bogina, Vice-Chairperson

House Members	Senate Members
Rep. Ann Cozine	Sen. Paul Burke
Rep. Duane Goossen	Sen. Ross Doyen
Rep. Henry Helgerson	Sen. Frank Gaines
Rep. Sheila Hochhauser	Sen. Nancy Parrish
Rep. Jo Ann Pottorff	Sen. Doug Walker
Rep. Tim Shallenburger	Sen. Wint Winter, Jr.
Rep. Jack Sluiter	
Rep. Galen Weiland	
Rep. Steve Wiard	

Public Members

Dr. Robert Harder
Mr. Larry McCants
Dr. Nancy McCarthy Snyder
Ms. Sandra McMullen
Dr. Chris Petr
Dr. Joe Reitz
Ms. Mary Sue Severance

The remainder of this report details the activities and recommendations of each Subcommittee. Recommended legislation will be introduced early in the 1992 Session.

SUBCOMMITTEE REPORTS

Subcommittee on Mental Health and Retardation Services Mental Retardation and Developmental Disability

<u>Summary</u>

1. General Conclusions

The Subcommittee makes the following general recommendations concerning community support services for mentally retarded or otherwise developmentally disabled individuals:

- A comprehensive array of support and direct services should be developed in Kansas which provide the greatest possible degree of integrated service options to mentally retarded or otherwise developmentally disabled people. This array of services shall be enhanced in partnership with individuals served, their parents, advocates, service providers, and federal, state, and local governments.

- The system of services to Kansans with mental retardation and developmental disabilities must be flexible and based on individual needs. Services shall be offered at a time and place which does not segregate or stigmatize individuals, in a way which provides diverse service options based on the following principles:

    - It is the responsibility of service providers to justify separate, nongeneric, or more restrictive services -- whether in special education, living arrangements, leisure opportunities, or work.

    - All individuals have the right to due process.

    - All individuals and/or their guardians shall have opportunities to make informed choices including, but not limited to, where to live, work, and play. They shall select and keep possessions, be treated with respect and live in surroundings that provide individuality and privacy.

    - All individuals shall be dealt with in an equitable manner.

    - Each individual shall receive services tailored to address their unique personal strengths and needs rather than based on the availability of services.

    - Individuals shall have the opportunity to have a safe, clean, and healthy environment.

    - All services shall continually meet at least minimum quality standards.

    - Services and the administration, management, and oversight of services shall be provided in the most cost effective manner possible.

- All individuals and agencies shall advocate resources and services which are in keeping with these principles. This advocacy shall be guided by individuals who are mentally retarded or otherwise developmentally disabled, their families, friends, and guardians. Advocacy shall include service agencies, county, state and federal agencies, elected officials, and the general public.

The following new ideas should be embraced by the state and community service providers:

- Decisions should be based on future planning for individuals rather than "slots" in the system. Service coordinators should then be trained to implement such decisions.
- Nuclear and surrogate families should be paid to provide a home for children as an alternative to public and private institutions.
- Money should be allocated in such a way that services are wrapped around the individual based on a level of need; rather than funding facilities, programs, or services.
- The system should consider people before disabilities, facilities, systems, or bureaucracies, and should encourage the use of generic services rather than segregated, specialized services.

2. Legislation

The Subcommittee recommends that legislation be introduced to enlarge the statutory description of mental retardation to include mental retardation and developmental disabilities (MR/DD) such as autism, cerebral palsy, epilepsy, or other similar physical or mental impairment. The definition, set out in detail below, further defines mental retardation.

The Subcommittee also recommends passage of H.B. 2530, currently in the House Committee on Public Health and Welfare. This bill would allow the delegation of noninvasive nursing procedures in community settings that service persons with developmental disabilities.

3. Community Mental Retardation/Developmental Disability Programs

The Subcommittee adopts a five-year plan presented by Mental Health and Retardation Services (MHRS) (see Table I). According to the plan, the 1,400 clients currently on the waiting list for community services will receive full community service by 1995; the census of the state mental retardation hospitals will be reduced by 83 clients a year, to 497 by 1997; all children with MR/DD will be served by 1995; all large bed intermediate care facilities for mental retardation will be eliminated by the year 2000 by reducing their census by 67 persons per year; and a service coordination mechanism will be developed which should serve 10,500 persons by 1997.

The Subcommittee's report concludes that the infrastructure of the community system must be strengthened so that the needs of individuals are met. The Subcommittee makes six recommendations to develop a high quality service infrastructure. These recommendations are set out in the report.

The Subcommittee recommends that a comprehensive array of support and direct services be developed which provide the greatest possible degree of integrated service options to MR/DD people. This array

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of services shall be enhanced in partnership with individuals served, their parents, advocates, service providers, and federal, state, and local governments. Furthermore, services shall be offered at a time and place which does not segregate or stigmatize individuals, in a way which provides diverse service options based on nine principles which are enumerated in the report.

The Subcommittee recommends that decisions should be based on future planning for individuals rather than "slots" in the system. Service coordinators should then be trained to implement such decisions; nuclear and surrogate families should be paid to provide a home for children as an alternative to public and private institutions; money should be allocated in such a way that services are wrapped around the individual based on a level of need; the system should consider people before disabilities, facilities, systems, or bureaucracies, and should encourage the use of generic services rather than segregated, specialized services.

The Subcommittee recommends that recognized community mental retardation centers (CMRCs) provide all service coordination (targeted case management) for MR/DD adults. Additionally, the Subcommittee adopts a funding proposal presented by MHRS which utilizes a Medicaid matching process called "certified match."

4. Hospital Consolidation

The Subcommittee believes that decisions must be made for the ultimate benefit of the client and notes that the trend, nationwide, is to place as many individuals into community settings as possible.

The Subcommittee recommends that, as a result of implementation of the community services plan as articulated by the Subcommittee report, one state mental retardation hospital should be closed by FY 1995. It is not the intention of the Subcommittee, through this recommendation, to recommend the abandonment of state hospitals. The Subcommittee believes, however, that consolidation of existing hospitals is an appropriate issue for legislative review.

The Subcommittee recommends that a determination regarding which state mental retardation hospitals should be closed, or consolidated, be made by the Department of Social and Rehabilitation Services (SRS). The Subcommittee propounds several factors for SRS to consider when making this decision. These factors are enumerated in the report.

The Subcommittee also recommends that SRS be given the authority to contract with consultants to assist it in implementing the Subcommittee's recommendation.

The Subcommittee recommends that community programs give special consideration to hiring those hospital workers who are displaced by hospital consolidation or staff reductions, provided the workers are qualified for the particular community job.

5. Vocational Rehabilitation and Special Education

The Subcommittee recommends that a stable staff of transition counselors be utilized to provide direction and assistance; and to work actively with families, students, education, and community providers for long-range transition planning.

The Subcommittee recommends that special education be closely monitored and returned to at least a 90 percent funding level.

6. Autism

The Subcommittee recommends the establishment and funding of a Kansas Resource Center on Autism.

7. Directions to Agencies

The Subcommittee requests a study be undertaken during the next legislative session, by SRS, to evaluate whether combining the funding of the state mental retardation hospitals and community programs is advisable.

The Subcommittee directs MHRS to establish standards for community development centers, core services, quality assurance, and quality enhancement. In addition, MHRS should establish minimum knowledge and performance competency levels for professional and paraprofessional personnel within the community.

The Subcommittee directs MHRS to work at establishing funding relationships with county governments.

The Subcommittee recommends that MHRS work with the Kansas Department of Transportation (KDOT) to review its rules and regulations to determine whether current methodology for operating costs is in keeping with the maximum cost in reimbursement allowances permitted by the federal government.

The Subcommittee also directs KDOT to ascertain whether Kansas' transportation policy is in compliance with the federal Americans With Disability Act, and to bring its conclusion to the attention of the House Appropriations and Senate Ways and Means SRS Subcommittees and the Transportation committees, during the 1992 Legislative Session.

Finally, the Subcommittee encourages the vocational rehabilitation system and the Department of Education (through special education) to work together to strengthen these programs.

Background

There are approximately 15,200 people with mental retardation and other developmental disabilities living in the State of Kansas. Of these, 65.9 percent have mental retardation, 20.9 percent have head injuries, 6.3 percent are epileptic, 5.1 percent have cerebral palsy, and 1.9 percent are autistic. About 7,300 (48 percent) of the mentally retarded/developmentally disabled population are children under the age of 21. Most mentally retarded or developmentally disabled people have additional disabilities. Approximately 30 percent have been diagnosed with psychiatric disorders.

In addition to the 986 persons in state hospitals, approximately 6,039 individuals are served in the community or in private, large-bed, intermediate care facilities (ICFs/MR). According to SRS, Division of MHRS, about 1,000 persons are served in private ICFs/MR, about 1,700 reside in a variety of community residential settings and just over 4,000 persons are served by 27 CMRCs. Over 1,500 persons served by CMRCs live at home with relatives; 300 live alone; 200 are in individual integrated living arrangements; 30 children live in foster care; and about 6,400 are children in special education programs in Kansas schools.

Kansas has three state hospitals or institutions for the mentally retarded -- Parsons State Hospital and Training Center, Winfield State Hospital and Training Center, and Kansas Neurological Institute (KNI), which serves approximately 986 clients. Kansas had four state hospitals for the mentally retarded until the closure of Norton State Hospital in 1988. In addition to mental retardation, many of the clients at these institutions have severe sensory and motor disabilities, behavior problems, chronic health conditions, and severe communication disorders. According to MHRS, there are more persons with severe or profound mental retardation in the community than there are in state institutions.

During the 1990 Legislative Session, a House Appropriations Subcommittee, while working with the budgets of the state mental retardation hospitals, recommended the closure of one of the hospitals. The corresponding Subcommittee of the Senate Ways and Means Committee did not agree. A compromise transpired when the 1990 Legislature mandated "that of the moneys appropriated for SRS for the current fiscal year, [FY 1991] expenditures shall be made for the development and implementation of a plan which shall be submitted by the secretary of SRS to the legislature on or before January 15, 1991, and which makes provisions to move a total of at least 50 clients from KNI, Parsons State Hospital or Winfield State Hospital into community placements and community facilities for persons who have mental retardation or other developmental disabilities. The plan shall include a detailed proposal covering:

1. the plan's impact on families of clients and staff at all three institutions;
2. the number of clients that the secretary of social and rehabilitation services anticipates will be placed into the community from each institution;
3. the status of available community facilities;
4. recommended funding alternatives for the placements;
5. identification and location of the one or more wards, cottages, units or equivalent client facilities to be closed at one or more designated institutions pursuant to the plan;
6. a breakdown of the number of clients, the level of mental retardation, physical handicaps and psychological impairment of the clients designated to be moved from the one or more closed wards, cottages, units or equivalent client facilities;
7. a specific plan for the reduction of staff at each designated institution and an evaluation of whether additional staff will be required at the other institution or institutions;
8. a review of the use of alternative Medicaid financing options, such as waiver availability for group homes and the personal care option as noted in the March, 1990 report presented to the above agency by the national association of state mental retardation directors; and
9. a recommended target date of June 1, 1991 to place as many additional institution clients from the waiting list as possible into the community throughout fiscal year 1991."

During the 1991 Session, the Legislature adopted a plan proposed by MHRS which called for downsizing the three state mental retardation institutions by a total of 113 clients. Under this plan, by the end of fiscal year 1992, the census of Winfield State Hospital and Training Center will be 332 (down 58 clients); the census of KNI will be 310 (down 45 clients); and the census of Parsons State Hospital, if possible, will be 260 (down ten clients).

In addition, the 1991 Legislature recommended, in H.B. 2640 that "... expenditures may be made by the above agency for fiscal year 1992 from the social services clearing fund for a master planner and associated staff and operating expenditures for the purpose of developing a plan to close two state institutions ... one in fiscal year 1993 and one in fiscal year 1994; Provided, That recommendations made in such a plan selecting a specific mental health and a specific mental retardation institution shall include an analysis of the costs and savings associated with closure, including an analysis of the availability of community programs, an analysis of the community's economic ability to respond to the closure of the institution and future labor trends in each community ...." This section of the bill was vetoed by the Governor.

On July 8, 1991, the Governor sent a letter to Robert Harder, Acting Secretary of SRS requesting, for budget review purposes during the first part of November, a determination as to what the component parts of a study to close a state mental health or retardation hospital should include. The Governor opined that it was important to move with caution, and requested SRS to take into account "the question of an individual doing harm to themselves or others, the cost of care in the hospital or institution in contrast to care in the community, and the social and economic impact of a possible closing of a hospital or institution within the geographic area in which they are located." The Governor's letter asked for an integrated report on the subject and for a comprehensive assessment as to services available in the community. Her letter indicated that discussion of closing state hospitals was not budget driven, but "lie[d] in creating a system of care that serves our clients best."

The Task Force on Social and Rehabilitation Services was established as an ongoing study group by the Legislative Coordinating Council. The Task Force Subcommittee on Mental Health and Retardation Services studied the following topic:

1. Development of Community Services for the Mentally Ill and Mentally Retarded/Developmentally Disabled

Identification of what services and system changes must take place in the community to develop a full complement of services which would allow the closure of a state mental health and a state mental retardation hospital. Identification of gaps in the current community system and recommendations concerning the development of a community-based continuum of care to serve clients currently unserved in the community as well as current state hospital clients. Monitor mental health reform and the expansion of the HCBS-MR waiver and associated client movement. In addition, the Subcommittee would look at particular issues pertaining to persons with autism and would look at the needs of the family of an individual with a disability.

Subcommittee Activity

The Subcommittee first held hearings on August 12 and 13, 1991. Representatives of organizations and private individuals appeared on community and institutional mental retardation/developmental disability issues, with the primary focus on community services. Testimony included an update by the Special Committee on Community Services and Hospital Closings, an update of client movement from mental retardation hospitals to community programs, and a discussion of autism issues.

In addition to hearing testimony, the Subcommittee toured KNI and the Topeka Association of Retarded Citizens' sheltered workshop at the Topeka Industrial Park. In lieu of its September Subcommittee meeting, the Subcommittee participated in the "Uniting Our Vision" conference held on September 6 and 7, 1991. The conference dealt with the concerns of people with developmental disabilities. Conference sessions focused on early intervention, supported employment, family support, financing, community living, and transition planning.

Final Subcommittee meetings, held on October 16 and 30, 1991, focused on the results of the conference and the response of Mental Health and Retardation Services to issues raised during the conference. The Subcommittee also heard testimony from parents and family members of developmentally disabled persons who were concerned about the possible closure of state mental retardation hospitals, and who stressed the need for the state to maintain large state run hospitals or institutions.

Committee Activity

1. Closure and Consolidation of State Mental Retardation Facilities

The Subcommittee firmly believes that decisions must be made for the ultimate benefit of the client, and notes that the trend, nationwide, is to place as many individuals into community settings as possible. The Subcommittee begins its recommendations by defining the role of the state mental retardation hospitals. Since downsizing, closing, and consolidating the hospitals has been a recurrent theme throughout the last several legislative sessions, the Subcommittee's first recommendation is that, over the next five years, Kansas should downsize from three to two state mental retardation hospitals. The Subcommittee understands that consolidation of state hospitals will not return dollar for dollar savings.

This decision, on its face, seems to indicate that the Subcommittee does not support the use of large state-run institutions. This assumption is incorrect. The Subcommittee concludes that there is a significant and beneficial role for state mental retardation hospitals and institutions. The Subcommittee envisions a strong symbiotic relationship between community programs and hospitals in the state. With this recommendation, the Subcommittee intends to strike a balance between parental/guardian rights, family rights, and client rights. It is not the intention of this Subcommittee to recommend the abandonment of state hospitals. The Subcommittee believes, however, that consolidation of existing hospitals is an appropriate issue for legislative review.

As stated by the SRS Task Force in 1990, "all Kansans, including those with mental retardation and other developmental disabilities, have the right and should have the opportunity to participate and be integrated into the life of their community and to exercise options to choose where and with whom they live, where to work, to participate in preferred leisure activities, to be educated in schools of their choice in their neighborhoods . . . ." The Subcommittee reaffirms this language and concludes that choice should also include an institutional option. While the Subcommittee's goal is to streamline or consolidate institutions, an institutional setting should always be available for clients and their families; and as a safety net for those individuals who attempt to utilize community services but who are unable, for whatever reason, to live away from an institution.

The Subcommittee recommends that a determination regarding which state mental retardation hospital should be closed, or whether consolidation should be undertaken, be made by SRS. The Subcommittee further recommends that the decision be based on objective criteria rather than political or subjective standards. Any decision shall take into consideration, but not be limited to, the following factors:

1. the best interest of each client, including medical, housing, transportation, rehabilitation, and educational needs;

2. physical plant, *e.g.*, how much renovation will be necessary in the next few years to upgrade the facility;

3. geographical considerations, *e.g.*, the location of families of consumers, the physical location of a hospital, the proximity of available alternative community services;
4. the per diem cost of each hospital;
5. the economic impact of closing a hospital on its host community; and
6. the availability of employment alternatives for hospital workers.

The Subcommittee recommends that SRS be given the authority to contract with consultants to assist it in implementing the Subcommittee's recommendation. The Subcommittee also recommends that, as a result of implementation of the community services plan as articulated by the Subcommittee report, one state mental retardation hospital should be closed by FY 1995.

The Subcommittee further recommends that community programs give special consideration to hiring those hospital workers who are displaced by hospital consolidation or staff reductions, provided the workers are qualified for the particularly community job.

2. Five-Year Plan

In conjunction with the recommendation to close and consolidate a state mental retardation facility, the Subcommittee also adopts a five-year plan presented by MHRS (see Table I). According to the plan, the 1,400 clients currently on the waiting list for community services will receive full community service by 1995; the census of the state mental retardation hospitals will be reduced by 83 clients a year, to 497 by 1997; all children with MR/DD will be served by 1995; all large bed intermediate care facilities for mental retardation will be eliminated by the year 2000 by reducing their census by 67 persons per year; and a service coordination mechanism will be developed which should serve 10,500 persons by 1997. The Subcommittee believes that it is imperative to provide quality assurance to the consumers of community services and their families. This plan, which would eliminate the waiting list, should ensure adequate service for persons who have mental retardation or developmental disabilities in Kansas by 1997. Table 2 and Table 3 provide additional information concerning clients served by community services, community waiting lists, types of developmental disabilities, and the intelligence level of persons served in community and hospital settings.

The Subcommittee concludes that the infrastructure of the community system must be strengthened so that the needs of individuals are met. To develop a solid, high quality service infrastructure, the Subcommittee directs SRS to work cooperatively with community providers to implement the following recommendations. The Subcommittee does not intend, by this request, for SRS to write burdensome rules and regulations which inhibit the ability of local MR/DD service providers to carry out their mission. The Subcommittee believes that it is incumbent upon the state to form a cooperative partnership with community providers to fund these programs.

1. rename CMRCs Community Developmental Centers and establish a slate of services which shall be available in each service area;
2. set minimum standards for knowledge and performance competence for paraprofessional and professional personnel who serve persons in the developmental service system;
3. establish a statewide, state level presence in area SRS offices to validate the mechanisms and monitor service provision, service quality, and service planning;

4. establish quality enhancement processes and procedures which go beyond minimally acceptable standards and which are led by consumers and parents;

5. establish a minimum wage or other salary enhancements for community provider staff; and

6. establish reimbursement levels that are tied to the level of individual need instead of funding services based on labels and categories. For example, design model contracts which provide funding for people, not programs.

The Subcommittee recommendations assume that funding will wrap around each individual rather than each program serving the individual. To safeguard this concept, several conferees suggested that funding for the mental retardation hospitals be combined with funding for community programs. Thus, when a client moves from the institution into the community, a certain percentage of the funding could follow. (Not all of the funding could follow because as each client leaves a hospital, the per diem costs of the hospital increase.) Combining the funding of the hospitals and the community programs would enable SRS to make necessary adjustments as clients were moved. Some concern was voiced by community providers that if hospitals were threatened with decertification, money would be pulled from the community budgets to correct the deficiency. This was resolved with a suggestion that money could only flow one way -- from the hospital into the community. This, however, poses an additional dilemma. Currently, each hospital has a separate budget, while community funding is part of the SRS budget. If the budgets were combined and the money flowed one way into the community, hospital superintendents would not know what the actual budget was; financial management would be difficult. Also, if a client needed or wanted to use the "safety net" and return to the institution, it would not be possible to reverse the funding flow. Although intrigued by the notion of combination funding for institutions and community programs, the Subcommittee does not take a position on this issue. The Subcommittee, however, requests that further studies be undertaken by SRS during the next legislative session.

3. The "Uniting Our Vision" Conference

On September 6 and 7, 1991, the Subcommittee participated in the "Uniting Our Vision Conference; a Kansas Conference on People with Developmental Disabilities." Conference sessions focused on early intervention, supported employment, family support, financing, community living, and transition planning. At the end of each session, conference participants were asked to complete a survey addressing recommendations for possible legislative actions, state agency changes, and changes in the current service system. Survey recommendations were summarized by the Kansas Association of Rehabilitation Facilities (KARF) and presented to MHRS. A joint meeting was then held with KARF representatives, MHRS, parents, and other interested parties to discuss the conference results. The outcome of this discussion, plus additional testimony from parents and providers, was presented at the October 16, 1991 Subcommittee meeting. The following Subcommittee recommendations evolved from the "Uniting Our Vision" Conference:

A. Philosophy of Community Support Services

1. The Subcommittee recommends that a comprehensive array of support and direct services should be developed in Kansas which provide the greatest possible degree of integrated service options to mentally retarded or otherwise developmentally disabled people. This array of services shall be enhanced in partnership with individuals served, their parents, advocates, service providers, and federal, state, and local governments.

2. The system of services to Kansans with mental retardation and developmental disabilities must be flexible and based on individual needs. Services shall be offered at a time and

place which does not segregate or stigmatize individuals, in a way which provides diverse service options based on the following principles:

a. It is the responsibility of service providers to justify separate, nongeneric, or more restrictive services -- whether in special education, living arrangements, leisure opportunities, or work.

b. All individuals have the right to due process.

c. All individuals and/or their guardians shall have opportunities to make informed choices including, but not limited to, where to live, work, and play. They shall select and keep possessions, be treated with respect and live in surroundings that provide individuality and privacy.

d. All individuals shall be dealt with in an equitable manner.

e. Each individual shall receive services tailored to address their unique personal strengths and needs rather than based on the availability of services.

f. Individuals shall have the opportunity to have a safe, clean, and healthy environment.

g. All services shall continually meet at least minimum quality standards.

h. Services and the administration, management, and oversight of services shall be provided in the most cost effective manner possible.

i. All individuals and agencies shall advocate resources and services which are in keeping with these principles. This advocacy shall be guided by individuals who are mentally retarded or otherwise developmentally disabled, their families, friends, and guardians. Advocacy shall include service agencies, county, state and federal agencies, elected officials, and the general public.

The Subcommittee further recommends that the following new ideas be embraced by the state and community service providers:

1. Decisions should be based on future planning for individuals rather than "slots" in the system. Service coordinators should then be trained to implement such decisions.
2. Nuclear and surrogate families should be paid to provide a home for children as an alternative to public and private institutions.
3. Money should be allocated in such a way that services are wrapped around the individual based on a level of need; rather than funding facilities, programs, or services.
4. The system should consider people before disabilities, facilities, systems, or bureaucracies, and should encourage the use of generic services rather than segregated, specialized services.

B. Professional Standards

The Subcommittee believes that there are a large number of very competent providers of community services within the state; however, testimony indicates that there are no uniform standards of care for service providers. The Subcommittee directs MHRS to establish standards for Community Development Centers, core services, quality assurance, and quality enhancement. In addition, MHRS should establish minimum knowledge and performance competency levels for professional and paraprofessional personnel within the community.

C. Noninvasive Medical Procedures

The Subcommittee recommends passage of H.B. 2530, currently in the House Committee on Public Health and Welfare, which would allow the delegation of noninvasive nursing procedures in medical care facilities, adult care homes, or elsewhere to persons not licensed to practice nursing if supervised by a registered nurse or a licensed practical nurse. The Subcommittee believes that basic medical procedures, often performed at home by family members, should be available in all community settings serving persons with developmental disabilities.

D. Local Support

The Subcommittee reviewed information regarding the establishment of local support for community mental retardation and developmental disability facilities. The Subcommittee learned that in 1969 the Legislature authorized counties to establish mill levies to fund services to individuals who are mentally retarded or otherwise developmentally disabled.

In 1974, the Legislature authorized state aid funding as a match for local funding efforts. In early years, local funding exceeded state funding. In recent years, however, this has changed. Testimony indicated that from 1988 to 1991, county contributions increased 17 percent while state contributions (including social service block grants) increased 76 percent. Virtually all service expansion in community services in the last several years is a result of increased state and federal funds.

There are 27 recognized community mental retardation centers in Kansas. All but one CMRC provides services to individuals who are mentally retarded or otherwise developmentally disabled. These CMRCs are local agencies directly receiving county mill funds and state aid. The Subcommittee heard a proposal from MHRS which would establish a partnership with counties to provide services to individuals which are not Medicaid funded. When services are expanded to individuals which cannot be funded by Medicaid, the state would provide 60 percent of the cost and the local counties would provide 40 percent.

The Subcommittee makes no recommendation on this proposal but directs the Department of Mental Health and Retardation Services to work at establishing funding relationships with county governments.

E. Service Coordination

Service coordination, frequently called targeted case management, provides MR/DD individuals and their families with guidance, assistance, and advocacy in securing necessary services. Service coordinators guide people through the maze of federal, state, and provider bureaucracies to obtain services specifically designed for their needs. The Subcommittee learned that Kansas does not have a comprehensive service coordination system. CMRCs, state hospitals, and private ICFs/MR all provide some coordination services. However, services provided by these organizations are limited; not only by existing resources, but also by the services each agency usually performs.

The Subcommittee recommends that recognized CMRCs provide all service coordination for adults with MR/DD. Additionally, the Subcommittee adopts a funding proposal presented by MHRS which utilizes a Medicaid matching process called "certified match." Using this approach, community agencies would provide service coordination to everyone who requests it in their service area. The CMRC would bill SRS for the service and certify that it has already received the state Medicaid match in the form of SRS grants awarded to it within current appropriations. SRS would then pay only the federal matching portion of the cost of services. The Subcommittee notes that this approach would require specially trained SRS staff in regional areas to monitor the quality of services and case management provided by the CMRCs, at an estimated cost of $500,000 to $1,500,000. The Subcommittee believes, however, that this strategy is the most cost effective option available. Service coordination is a critical starting point for a successful statewide community program.

F. Transportation

The Subcommittee learned, during the "Uniting Our Vision" conference, that families have routinely complained of lack of transportation to and from available community services. The Subcommittee notes that K.S.A. 75-032 *et seq.*, refers to the Elderly and Handicapped Public Transportation Assistance Act. The Act established the Elderly and Handicapped Coordinated Public Transportation Assistance Fund and directs the Secretary of the Kansas Department of Transportation (KDOT) to develop a plan to implement the Act. The Act defines transportation as "the movement of individuals and meals in a four or more wheeled motorized vehicle designed to carry passengers. Transportation does not include emergency or school transportation." The Subcommittee recommends that MHRS work with KDOT to review its rules and regulations to determine whether current methodology for operating costs is in keeping with the maximum cost of reimbursement allowances permitted by the federal government. The Subcommittee also directs KDOT to ascertain whether Kansas' transportation policy is in compliance with the federal Americans With Disability Act, and to bring its conclusion to the attention of the House Appropriations and Senate Ways and Means SRS subcommittees and the Transportation committees during the 1992 Session.

G. Family Subsidy Pilot Project

The Subcommittee notes with approval that the 1991 Legislature implemented a family subsidy pilot project for respite care. In addition, MHRS has allowed more flexibility through special purpose grants, the HCBS waiver for respite care, van lifts, and home modifications. Testimony provided by MHRS indicates that the family subsidy program should be in operation by December 1, 1991. The Subcommittee applauds efforts made by MHRS to implement this program and recognizes that the program expands options and alternatives for families and community living.

H. Vocational Rehabilitation

The Subcommittee heard testimony from community providers regarding the need to strengthen the transitional vocational rehabilitation system. Testimony indicated that traditionally, adults with developmental disabilities have received training for employment through sheltered workshops. These workshops have served many purposes such as training people for community employment, providing a paid work environment, providing an environment where people with disabilities have the necessary support to enable them to work, and providing an alternative means of funding community programs. Recent trends, however, allow job placement directly into the competitive work environment or through the supported employment model which provides supports for the individual at the work site.

The Subcommittee encourages the vocation rehabilitation system and the Department of Education (through special education) to work together to strengthen vocational rehabilitation programs. In particular, the Subcommittee recommends that a stable staff of transition counselors be utilized to provide direction and assistance and to work actively with families, students, education, and community providers for long-range transition planning.

I. Special Education Programs

The Subcommittee expresses concern regarding the underfunding of Special Education programs. Testimony indicated that some public schools were cutting services rather than expenses. The Subcommittee recommends that special education funding be closely monitored and returned to at least a 90 percent funding level. Currently, special education is at a 73 percent funding level.

4. Autism

In addition to the mental retardation and developmental disability concerns discussed above, the Subcommittee also specifically focused on one particular developmental disability -- autism. Autism is a developmental disability which affects an individual's communication skills, social perceptions, and learning rate. It is a neurological disorder of the brain, frequently accompanied by disruptive, self-injurious, or aggressive behavior, stereotypic body movements, and a preoccupation with objects. There is no known cure. The 1987 Task Force Report on Autism estimated that there were 3,654 autistic individuals in Kansas at that time.

The Subcommittee learned that services are often not available to persons with autism and that individuals are frequently placed in settings inappropriate to their needs. Because professionals are untrained or unfamiliar with this disorder, parents and volunteers have shouldered the primary responsibility of providing programming suggestions, information, referrals, and even training of caretakers and providers.

The Subcommittee recommends the establishment of the Kansas Resource Center on Autism to provide a source for:

1. information on autism;
2. a central registry for autism for tracking purposes and statewide needs assessment;

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3. formation of specific training agreements and consultations with agencies to train agency staff to use the positive intervention strategy;

4. training, technical assistance, and consultation to teachers, advocates, and friends and family members of people with autism;

5. collect, update, and present information on autism to various professionals, families, community agencies, and the public;

6. provide parents and families with information and problem solving techniques;

7. provide accurate, timely information to state agencies and legislators, to facilitate networking, and to advocate for best practices; and

8. increase public awareness through new videotaped productions and literature.

The Resource Center would provide existing agencies and providers with the latest methods and practice in addressing this disorder. Approximate cost of the resource center would be $135,400. Estimated expenditures would include salaries and wages for three FTE (two professionals and one support person ($91,000)); rent ($6,000); travel ($19,200); communications ($4,700); staff training ($6,200); program equipment ($3,000); and a resource library ($4,100).

5. Uniting the Vision

In addition to the establishment of a Resource Center for Autism, the Subcommittee recommends legislation enlarging the statutory description of mental retardation to include mental retardation and developmental disabilities. As established by the "Uniting Our Vision" Conference, the Subcommittee believes that people with developmental disabilities and their families have unique needs, which are often inadequately addressed by community services. Services which should be available to all disabled individuals are often selectively doled out to those who fit only within a narrow statutory definition. The theme of the conference was unity, and it is the Subcommittee's unanimous recommendation that all persons with developmental disabilities be united through legislation which defines mental retardation <u>and</u> other developmental disabilities as follows:

Mental retardation means significantly sub-average intellectual functioning existing concurrently with deficits in adaptive behavior. Other developmental disability means a condition such as autism, cerebral palsy, epilepsy, or other similar physical or mental impairment. In addition, mental retardation and otherwise developmentally disabled, also, means a severe, chronic disability which:

1. is attributable to a mental or physical impairment or a combination of mental and physical impairments, AND

2. is manifest before the age of 22, AND

3. is likely to continue indefinitely, AND

4. results in substantial limitations in any three or more of the following areas of life functioning:

    a. self-care,

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b. understanding and the use of language,

c. learning and adapting,

d. mobility,

e. self-direction in setting goals and undertaking activities to accomplish these goals,

f. living independently, and

g. economic self-sufficiency, AND

5. reflects a need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are lifelong, or extended in duration and are individually planned and coordinated, AND

6. does not include individuals who are solely severely emotionally disturbed or seriously and persistently mentally ill or have disabilities solely as a result of infirmities of aging.

Rep. Gary Blumenthal, Subcommittee
  Chairperson
Rep. Henry Helgerson, Subcommittee
  Vice-Chairperson
Rep. Ann Cozine
Rep. Tim Shallenburger
Sen. Wint Winter, Jr.
Ms. Sandra McMullen

Pro. No. 19

27-1

TABLE I

Estimated Costs of Providing Full Services for Persons
Who have Mental Retardation or Developmental Disabilities
in Kansas by 1997
As recommended by the 1991 MH&RS Legislative Subcommittee

Revised 01/03/92

SERVICE TYPE	--------FY 93--------			--------FY 94--------			--------FY 95--------			---------FY 96-------			--------FY 97--------		
	Persons Served	SGF Cost (millions	FED Cost (millions	Persons Served	SGF Cost (millions	FED Cost (millions	Persons Served	SGF Cost (millions	FED Cost (millions	Persons Served	SGF Cost (millions	FED Cost (millions	Persons Served	SGF Cost (millions	FED Cost (millions
Service Coordination	5064	$0.00	$3.04	6162	$0.50	$3.85	7118	$0.75	$4.62	8070	$1.00	$5.45	9000	$1.50	$6.32
Supported Employment/Supported Living Services															
* VR Matching Grants	75	$0.40	$1.80	75	$0.40	$1.80	75	$0.40	$1.80	75	$0.40	$1.80	75	$0.40	$1.80
* MH&RS Continuation Grants	75	$1.00		150	$2.07		225	$3.23		300	$4.48		375	$5.84	
* State General Funds	218	$2.45		436	$5.09		654	$7.94		872	$11.00		1090	$14.34	
Medical Services															
* HCBS/MR Recipients	1218	$1.75	$2.63	1615	$2.33	$3.49	1900	$2.74	$4.10	2166	$3.12	$4.68	2470	$3.56	$5.34
* SGF Recipients	3816	$3.82		4176	$4.18		4544	$4.54		4837	$4.84		5130	$5.13	
Day and Residential Habilitation Services															
* Existing SGF Services(incl.SS	3478	$30.98		3478	$30.98		3478	$30.98		3478	$30.98		3478	$30.98	
* COLA for Existing Services		$1.24			$2.53			$3.87			$5.27			$6.82	
* Existing HCBS/MR Recipients	786	$7.58	$11.37	786	$8.35	$12.52	786	$9.12	$13.68	786	$9.48	$14.22	786	$9.86	$14.79
* New HCBS/MR Recipients	108	$1.04	$1.56	358	$3.80	$5.70	466	$5.41	$8.11	570	$6.88	$10.31	712	$8.93	$13.40
* Reduce Institutions using HCB															
State Institutions	190	$3.46	$5.19	273	$5.17	$7.76	356	$7.02	$10.53	439	$9.00	$13.50	510	$10.90	$16.35
Private Institutions	134	$1.63	$2.44	213	$2.69	$4.04	292	$3.84	$5.76	371	$5.07	$7.60	402	$5.73	$8.59
Family Support Services															
* Family Subsidy	400	$1.20		800	$2.40		1200	$3.60		1600	$4.80		2000	$6.00	
* Other Family Support Services	144	$0.43		288	$0.86		432	$1.29		576	$1.73		719	$2.16	
Agency Support Services															
* SRS Field Staff		$0.25	$0.25		$0.26	$0.26		$0.27	$0.27		$0.28	$0.28		$0.29	$0.29
* Local Consumer Councils		$0.41			$0.42			$0.44			$0.46			$0.47	
* CMRC Staff Training		$0.79			$1.15			$1.43			$1.71			$1.98	
* Bi-Annual Needs Assesment		$0.22			$0.24			$0.26			$0.28			$0.29	
* Rate Setting Study		$0.20													
Institutional Services															
* Three State Institutions	829	$27.36	$41.04	746	$26.80	$40.20	663	$26.16	$39.24	580	$25.41	$38.12	497	$21.34	$29.48
* Large Private ICFs/MR	516	$7.32	$10.98	437	$6.70	$10.04	358	$5.93	$8.89	279	$4.99	$7.48	200	$3.86	$5.79
* Small Private ICFs/MR	346	$7.37	$11.05	346	$7.95	$11.93	346	$8.59	$12.89	346	$9.27	$13.91	346	$10.02	$15.07
Total (Unduplicated)	7155	$100.90	$91.36	8098	$114.87	$101.59	8899	$127.80	$109.87	9696	$140.44	$117.36	10471	$150.41	$117.23
FY 92 SGF $82.85 mm Inflated		$86.16	$68.90		$89.61	$71.66		$93.21	$74.53		$96.93	$77.51		$101.08	$8.08
Additional State General Funds		$14.73	$22.46		$25.26	$29.93		$34.59	$35.34		$43.51	$39.85		$49.34	$109.15

NOTES:
1. This sheet estimates costs for a full service system for persons who are developmentally disabled.
2. This sheet does not reflect SRS appropriation requests due to limited state resources.
3. This sheet does not reflect SGF costs for service coordination because existing SGF will be used as certified Medicaid match.
4. Most funds on this spread sheet, including the $82.55mm appropriated for fy 92, were inflated 4% per year.
5. This sheet does not include any additional support from local counties.
6. In FY 97 Kansas will consolidate from three state mental retardation hospitals to two.

Prepared by Mental Health and Retardation Services.

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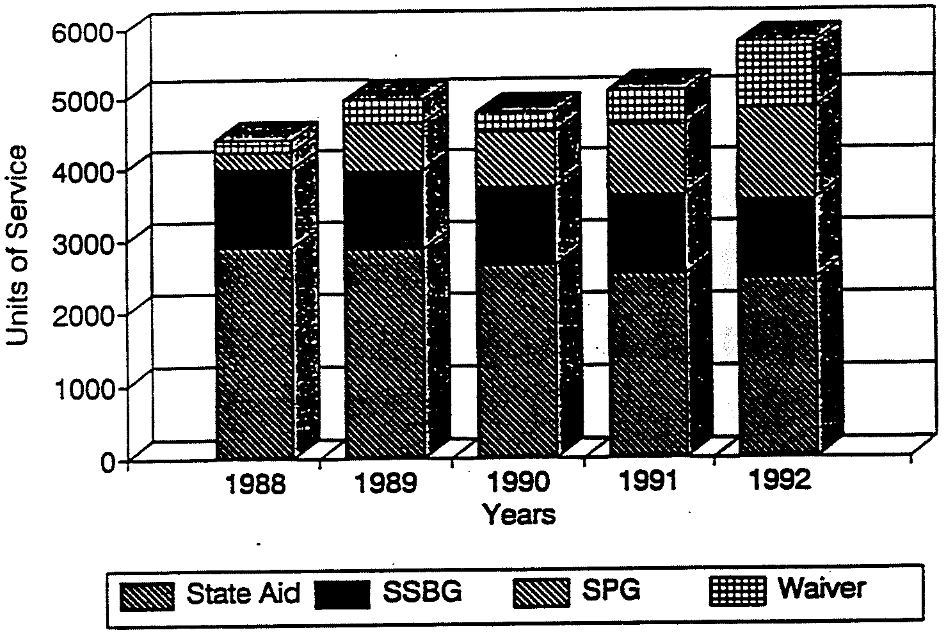
Table 2

Persons Served by Community Units of Service

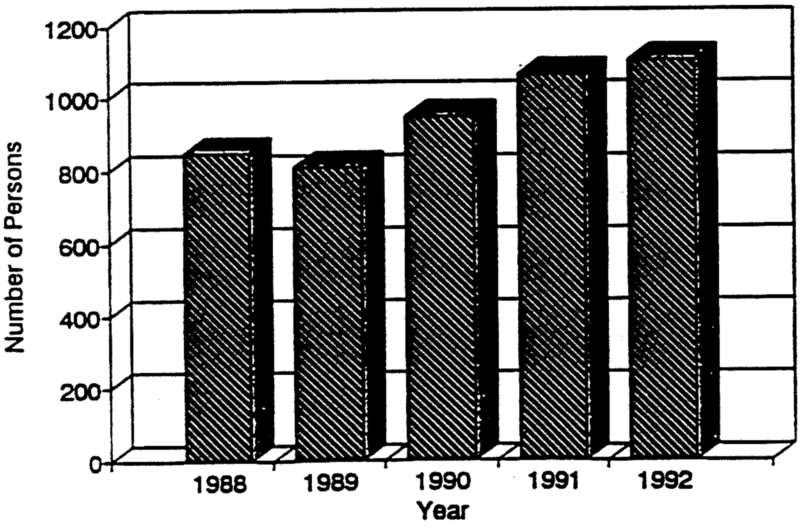
in Kansas 1988-1992



- There has been a real increase in the number of persons served, as the mix of funding changed (State Aid, Title XX Social Service Block Grant, Special Purpose Grants, and Home & Community Based Services Waiver), and as community services capacity building became a priority

People Waiting for Service at CMRCs

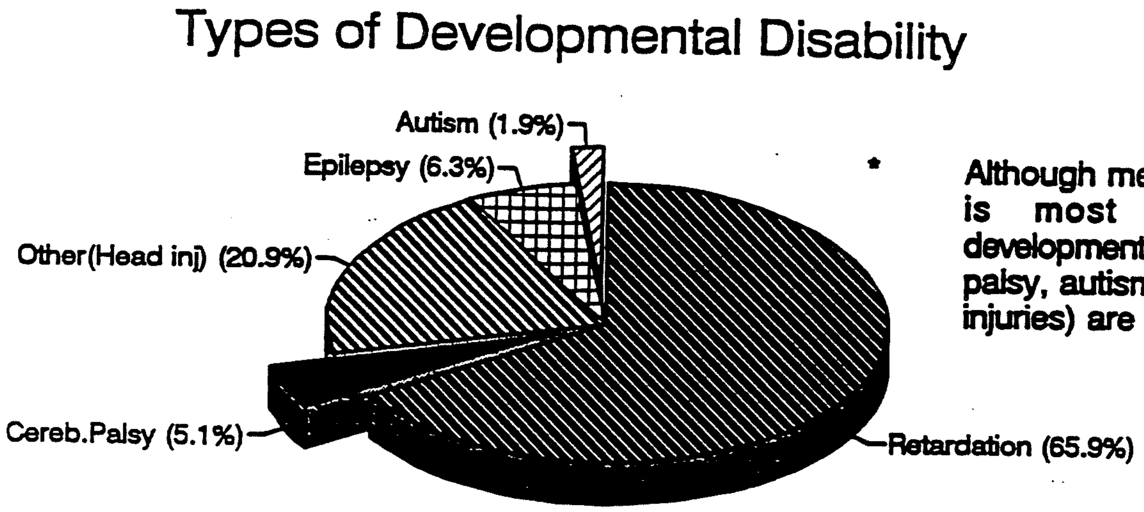
in Kansas 1988-1992



- Over 1,100 persons (children & adults) are waiting for community based services

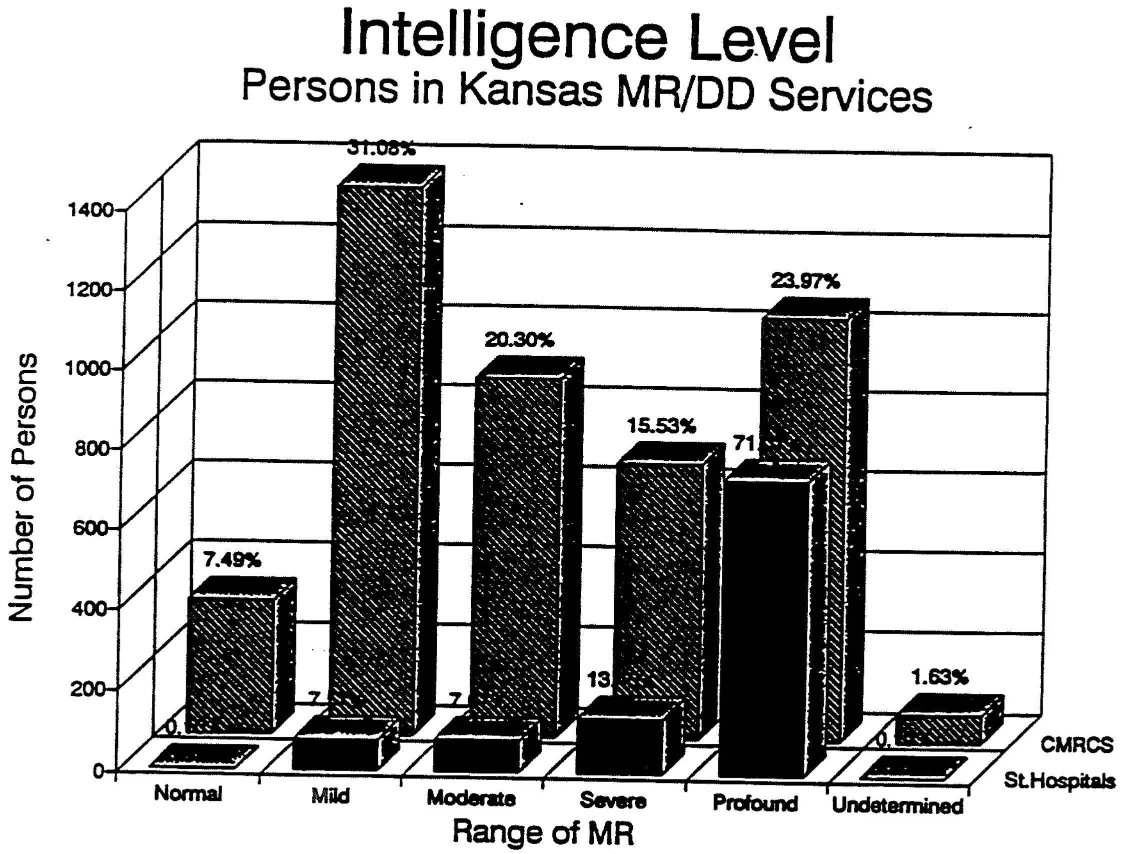
Prepared by Mental Health and Retardation Services.

Table 3



Types of Developmental Disability

* **Although mental retardation is most prevalent, other developmental disabilities (cerebral palsy, autism, epilepsy, and head injuries) are included**



Intelligence Level

Persons in Kansas MR/DD Services

Prepared by Mental Health and Retardation Services.

* There are more persons with severe or profound mental retardation in the community than there are in state institutions

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Subcommittee on Mental Health and Retardation Services
Mental Health Issues

Summary

1. General Conclusions

The Subcommittee recommends continuation of the mental health reform plan and notes the following general goals of mental health reform:

- Mental health reform is intended to close gaps in service provision, to provide a continuum of care through community programs, and to improve the quality of care received by Kansans needing mental health services.
- Through the continuation of mental health reform, community treatment should be a readily available, viable treatment alternative to admission to a state hospital.

The Subcommittee makes recommendations regarding mental health services for seriously emotionally disturbed children and adolescents and notes the following general observations:

- Children and adolescents with serious emotional disturbances and their families should have access to an array of affordable services that are flexible and developed according to individually identified needs.
- All children should live in family settings unless they clearly present an imminent danger to society. If adequate support services are available, families can receive the support they need to maintain children in their own homes and schools. Such services would include case management, day treatment, crisis response, home-based family intervention, attendant care, respite care, after school programs, and summer programs.
- Services among systems should be coordinated among all the agencies involved and should be designed so that they are child and family centered with the goal of maintaining a child in, or returning a child to, the child's family.
- Children and families should not have to fit into existing programs and services. Services should be developed to fit the needs of the child and family, and should be "wrapped around" the child and family.
- Services should be culturally sensitive.
- The services system should be outcome oriented.
- Services common to most communities, such as recreation, volunteer, employment, and latchkey services, school related activities, and summer camps, should be used to provide a full, active, integrated life for all children.

2. Closure and Consolidation of State Mental Health Hospitals

The Subcommittee concurs with the continued downsizing of the state mental health hospitals through continuation of the mental health reform plan, but does not take a specific position on closure of a state mental health hospital. The Subcommittee notes, however, that any consideration of closure of a state mental health hospital is dependent upon the development of strong community-based mental health programs.

3. Screening of Medicaid Eligible Clients Before Admission to Private Facilities

The Subcommittee endorses an SRS plan for community mental health center screening of all Medicaid eligible persons before admission to private facilities for mental health treatment and directs SRS to report on the progress of the plan during the 1992 Legislative Session.

4. Nursing Facilities for Mental Health

In response to reports of inappropriate placements and patient abuse or neglect in nursing facilities for mental health (NFs-MH), the Subcommittee reports several facts about the NF-MH program and notes factors contributing to the NF-MH situation.

The Subcommittee reports the preliminary recommendations of a task force made up of NF-MH administrators and representatives of SRS and community mental health centers.

The Subcommittee concludes that Mental Health and Retardation Services (MHRS) should continue to have programmatic responsibility for the NF-MH facilities, that MHRS should continue to work to develop standards specific to NFs-MH, and that MHRS should be given adequate funding for quality assurance, monitoring, and oversight of the NF-MH facilities. The Subcommittee directs SRS to present more specific recommendations to the House Appropriations and Senate Ways and Means Subcommittees during the 1992 Legislative Session.

5. Children's Mental Health Services

The Subcommittee describes principles and values inherent in a mental health services system for seriously emotionally disturbed children and adolescents. The Subcommittee concludes that continuation of mental health reform would provide the beginning steps in the development of such a system and recommends continued funding of mental health reform.

6. Mental Health Reform Pilot Project for Children and Adolescents

The Subcommittee recommends that SRS be provided with adequate funding to implement the provisions of Section 11 of the Mental Health Reform Act, which authorizes the Secretary of SRS to enter into a contract for a pilot project to provide the Medicaid services related to psychiatric and substance abuse services for Medicaid eligible persons under the age of 21.

7. Regional Interagency Councils

The Subcommittee recommends legislation establishing regional interagency councils to develop and implement individual service plans for seriously emotionally disturbed children and adolescents. The membership and actions of the councils are set out in detail below.

The areas served by the councils would correspond to the 12 SRS area office districts.

8. Additional Subcommittee Recommendations

The Subcommittee recommends that SRS devote additional study to two issues and report its findings to the 1992 Legislature. The first issue concerns review of the current statutory policy which relieves local school districts of financial responsibility for the educational responsibility of institutionalized children. The second issue involves funding of a family subsidy program for families of seriously emotionally disturbed children.

Background

The Task Force on Social and Rehabilitation Services directed the Mental Health and Mental Retardation Subcommittee to study the following topic during the 1991 interim:

> Identification of what services and system changes must take place in the community to develop a full complement of services which would allow the closure of a state mental health and a state mental retardation hospital. Identification of gaps in the current community system and recommendations concerning the development of a community-based continuum of care to serve clients currently unserved in the community as well as current state hospital clients. Monitor mental health reform and the expansion of the HCBS-MR waiver and associated client movement.

This portion of the Subcommittee's report details the Subcommittee's activities, conclusions, and recommendations concerning mental health issues.

1. Mental Health Reform

The Kansas mental health services delivery system has been the topic of numerous legislative studies in recent years. Legislative activity culminating in mental health reform legislation can be traced to the 1988 interim Special Committee on Ways and Means/Appropriations, which was directed to "review and make recommendations concerning a comprehensive plan for the delivery of mental health services . . . ." The Committee heard testimony from many mental health professionals and consumers before concluding that "numerous changes [were] needed in the existing structure of the mental health services delivery system if Kansas citizens [were] to receive appropriate and adequate mental health services."

Legislation recommended by the 1988 interim Special Committee on Ways and Means/Appropriations was referred to the House Appropriations Committee, which appointed a Subcommittee to further study the bill during the 1989 Legislative Session. The Subcommittee received additional testimony, deliberated the issues, and worked through several drafts of legislation before recommending the introduction of

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three other bills. The Subcommittee noted that its primary objective in recommending the bills was "to close the gaps in service provision which currently exist, to provide a complete continuum of care through community programs, and to improve the quality of care received by mentally ill Kansans." The Subcommittee further stated that its intention was to address mental health concerns "by strengthening and enhancing mental health services at the community level so that community treatment is a readily available, viable treatment alternative to admission to a state hospital." The Subcommittee did not recommend that any action be taken on the bills during the 1989 Session, but recommended that an interim committee review and receive further testimony on the three bills.

The 1989 interim Special Committee on Corrections/Mental Health reviewed the provisions of the three bills and received testimony from mental health services consumers, family members of consumers, mental health services providers, advocates, and other interested persons. The Committee agreed with the major concepts and structural components of the bills, but recommended a number of amendments, resulting in H.B. 2586. Two subcommittees of the House Appropriations Committee reviewed H.B. 2586 during the 1990 Legislative Session and received additional testimony before recommending Sub. H.B. 2586. Additional amendments were made by the Senate Committees on Public Health and Welfare and Ways and Means.

Sub. H.B. 2586, known as the Mental Health Reform Act, made numerous changes in the previous Treatment Act for Mentally Ill Persons which were intended to result in the provision of quality community-based mental health services. The Act specifies the manner in which mental health services are to be provided to a "targeted population," which is defined as the population group designated by the Secretary of Social and Rehabilitation Services as most in need of mental health services which are funded, in whole or in part, by state or other public funds.

The Act defines catchment areas and provides a schedule for the implementation of its provisions in the Osawatomie, Topeka, and Larned State Hospital catchment areas. As each catchment area is phased in to the program, the Secretary of SRS is to enter into contracts with mental health centers so that there is a participating mental health center for each area of the state. Once participating mental health centers are established, all state hospital admissions must be screened by a qualified mental health professional employed by a participating mental health center. The screening process determines whether a person, under either voluntary or involuntary procedures, can be evaluated or treated in the community or should be referred to the appropriate state hospital for evaluation or treatment. No patient shall be discharged from a state psychiatric hospital without receiving recommendations from the participating mental health center. The Act more fully defines the terms "screening," "qualified mental health professional," "participating mental health center," and other terms.

Section 10 of the Act provides a schedule for the closure of state hospital beds as mental health reform is phased into the state hospital catchment areas.

The Act specifies the powers and duties of the Secretary of SRS which include, among others, functioning as the sole state agency to develop a comprehensive plan to meet the needs of mentally ill persons; evaluating and coordinating all services, programs, and facilities provided by agencies that receive state and federal funds; adopting rules and regulations for targeted population members which provide that, within the limits of appropriations, no person shall be inappropriately denied necessary mental health services from any mental health center or state psychiatric hospital and that services shall be provided in the least restrictive manner; establishing and implementing policies and procedures so that funds from the state shall follow persons from state facilities into community programs; providing the least restrictive treatment and most appropriate community-based care through coordinated utilization of the existing network of mental health centers and state psychiatric hospitals; establishing standards for community support services and other community-based mental health services; assuring the establishment of specialized programs and service requirements for targeted populations within each mental health center in the state; reviewing and approving the annual coordinated services plan of each mental health center during each fiscal year ending after June 30, 1991, and withholding state funds from any mental health center which is not being administered substantially in accordance with the provisions of the annual coordinated services plan and budget submitted by the center to the Secretary; and adopting rules and regulations necessary

TASK FORCE ON

SOCIAL AND REHABILITATION SERVICES

REPORT AND RECOMMENDATIONS TO THE

1991 LEGISLATURE

Kansas Legislative Research Department
Room 545-N -- Statehouse
Topeka, Kansas 66612-1586

January, 1991

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INTRODUCTION

The Task Force on Social and Rehabilitation Services was established as on ongoing study group by the Legislative Coordinating Council and was charged for the 1990 interim under Proposal No. 36 with the following:

> Study and evaluate the administrative structure and functioning of the Department of Social and Rehabilitation Services, with an emphasis on improving the cost-effectiveness of the delivery of services; review the effectiveness of the administration of programs and functions with particular focus on reducing duplication in the delivery of services, improving cooperation among agencies and administrative units, and maximizing resources through better utilization of matching funds; review rules and regulations adopted by the federal government and the Secretary of Social and Rehabilitation Services to determine whether these regulations assist or hinder in the administration of programs and functions of the Department; and identify and evaluate causes of programmatic cost increases.

The Task Force consists of the following 17 legislative members and seven public members:

Senate Members

August Bogina, Jr., Chairperson
Paul "Bud" Burke
Ross Doyen
Frank Gaines
Nancy Parrish
Doug Walker
Wint Winter, Jr.

House Members

R.H. Miller, Vice-Chairperson
Bill Brady
Denise Everhart
Duane Goossen
David Heinemann
Joann Pottorff
Susan Roenbaugh
Carol Sader
Joan Wagnon
Tom Walker

Nonlegislative Members

Dr. Robert C. Harder
Mr. H. William Hopp
Mr. Larry McCants
Dr. John Poertner
Dr. Joe Reitz
Mr. Merrill Werts
Mr. Wint Winter, Sr.

The Task Force is divided into the following four subcommittees for purposes of studying the Department of Social and Rehabilitation Services:

Organizational Structure and Delivery of Services
Mental Health and Retardation Services
Medical Services
Children's Services

The four subcommittees held hearings and made recommendations for the 1990 interim and reported these to the Task Force. These reports were amended and adopted by the entire Task Force and make up the remainder of this report. Although the Task Force as a whole did not have the opportunity to review recommended bill drafts, legislation to implement Task Force recommendations will be drafted and introduced where indicated upon review by the Task Force Chair, Vice-Chair, and Designated Minority Member, as well as the Subcommittee Chair and Vice-Chair.

II. MENTAL HEALTH AND RETARDATION SERVICES

A. Mental Health Reform

The Task Force studied the issue of Mental Health Reform.

Background

Two years ago, a report was published which ranked Kansas second lowest among all states and "moving backwards" in regard to mental health programming. Major criticisms indicated that the system was too heavily dependent on state hospitals; there were too few acceptable community health programs; and there was no coordination between the state hospitals and community programs. In response to these issues, the 1990 Legislature passed Substitute for H.B. 2586 which is designed to address the perceived inadequacies of the state's public mental health system. The bill establishes a seven year phased program in which a specified number of state hospital beds for both children and adults will be reduced; while a corresponding number of beds will be developed in the community. The legislation also mandates a free flow of information between the hospitals and the community and establishes provisions that mandate cooperation between the hospital and the community providers.

Task Force Activity

The Director of Mental Health presented oral and written testimony regarding the implementation of mental health reform in Kansas. The Task Force learned that the Governor's Mental Health Services Planning Council has met for more than a year and has adopted a committee structure. Committees address the issues of children, housing, special populations, vocational development, financing, and human resource development.

In response to the requirements of the Mental Health Reform Act, the following transitions are taking place: (1) SRS staff has prepared a draft set of licensing standards for the mental health centers; (2) a committee is developing admissions and discharge criteria; (3) the 12 mental health centers in the Osawatomie State Hospital Catchment area are planning for the provision of new services within the area; (4) a draft contract for participating mental health centers which defines the services to be provided and the conditions of participation has been discussed with the mental health centers; (5) a task force has been established to address issues inherent in the transfer of the program authority for intermediate care facilities for mental health from Adult Services within SRS to Mental Health and Retardation Services; and (6) MHRS has developed a draft of a community needs assessment. The Mental Health Reform Act requires that a community needs assessment be conducted by each participating mental health center.

New section 11 of the Act requires that the Secretary enter into a contract for a pilot project for Medicaid services related to psychiatric and substance abuse for Medicaid eligible children. Although children are often eligible for Medicaid while hospitalized, eligibility may be lost when the child returns home because the parent's income is then considered in determining Medicaid eligibility. The feasibility of obtaining a Medicaid waiver, or some other option that will allow families to obtain Medicaid eligible services in the community, is being explored by SRS and by the Children and Adolescent Committee of the Governor's Mental Health Services Planning Council.

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Conclusions and Recommendations

The Task Force recognizes that the Mental Health Reform Act is new legislation and only in the first stage of implementation. The Task Force approves of the steps taken thus far regarding the implementation of the Act and recommends that no further studies be undertaken by themselves at this point in time. The Task Force recommends that the Legislature receive periodic updates from the Department of SRS regarding the status of the Act.

B. Client Movement from State Institutions

The Task Force requested an update from Mental Health and Retardation Services regarding 1990 H.B. 3120.

Background

The 1990 Legislature mandated "that of the moneys appropriated for SRS for the current fiscal year, expenditures shall be made for the development and implementation of a plan which shall be submitted by the secretary of SRS to the legislature on or before January 15, 1991, and which makes provisions to move a total of at least 50 clients from KNI, Parsons State Hospital or Winfield State Hospital into community placements and community facilities for persons who have mental retardation or other developmental disabilities. The plan shall include a detailed proposal covering (1) the plan's impact on families of clients and staff at all three institutions; (2) the number of clients that the secretary of social and rehabilitation services anticipates will be placed into the community from each institution; (3) the status of available community facilities; (4) recommended funding alternatives for the placements; (5) identification and location of the one or more wards, cottages, units or equivalent client facilities to be closed at one or more designated institutions pursuant to the plan; (6) a breakdown of the number of clients, the level of mental retardation, physical handicaps and psychological impairment of the clients designated to be moved from the one or more closed wards, cottages, units or equivalent client facilities; (7) a specific plan for the reduction of staff at each designated institution and an evaluation of whether additional staff will be required at the other institution or institutions; (8) a review of the use of alternative medicaid financing options, such as waiver availability for group homes and the personal care option as noted in the March, 1990 report presented to the above agency by the national association of state mental retardation directors; and (9) a recommended target date of June 1, 1991, for placement of 50 or more clients pursuant to such plan. Expenditures shall also be made by the department of social and rehabilitation services of moneys appropriated for fiscal year 1991 to place as many additional institution clients from the waiting list as possible into the community throughout fiscal year 1991."

Task Force Activity

The Task Force received written and oral testimony regarding the SRS plan from the Director of Mental Retardation. The projected budgeted census for the three mental retardation hospitals at the start of FY 1991 was 1,045 residents. A reduction to 50 residents translates into an on-site state hospital population of no

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more than 995 residents by June 1, 1991. The total hospital census as of October 18, 1990 numbered 1,015, a census reduction, to date, of 30 persons. This reduction occurred through the normal placement process.

The placement process involved willing residents, parents, and various facilities. There has been no specific impact on families or hospital staff to date. Of the 30 placements, 12 came from KNI, nine from Parsons State Hospital and Training Center, and nine from Winfield State Hospital and Training Center. Alternatives for funding the placement of the remaining 20 persons to meet the planned reduction are constrained. According to the Director, there are not sufficient resources to provide an adequate funding level for direct placements to community programs. Nevertheless, Winfield State Hospital and Training Center is committed to a further reduction in census of 20 persons with a concomitant reduction of ten staff in FY 1991. Placement into community slots are competing with an existing waiting list of 1,325. Clients waiting at the institutions are included in that number. In addition to the waiting list, the Task Force reviewed information addressing the demographics of recent state hospital placements, the length of stay for each individual, client intelligence levels, the ICF/MR cost updates, and proposed dorm renovations at Winfield State Hospital which MHRS recommends in conjunction with the client reduction at Winfield.

Conclusions and Recommendations

The Task Force recommends that the State of Kansas establish a policy directed towards serving individuals with disabilities closest to their home communities: the over-riding philosophy of services for children and adults with disabilities is to offer the opportunity to live, work, and participate in their community to the degree that they are able. The local, state, and federal governments should share in a partnership to provide this opportunity. All individuals, regardless of their disability, should have access to this community support system resulting in an inclusive society for those with disabilities. In light of this policy, the Task Force recommends that SRS begin planning for a reduction in the number of beds in state mental retardation institutions and report those plans by January, 1992. The Task Force believes that the state should place each client in the least restrictive environment possible. This rationale follows the Service Plan Outline developed by the Committee on Policy and Procedures pertaining to MR/DD services in Kansas. This advisory committee predicates its plan on the philosophy that: "all Kansans, including those with mental retardation and other developmental disabilities, have the right and should have the opportunity to participate and be integrated in the life of their community and to exercise options to choose where and with whom they live, where to work, to participate in preferred leisure activities, to be educated in schools of their choice in their neighborhoods and to build and maintain relationships with family and friends."

The Task Force believes that as state support for community programs increase, services will increase, alleviating the need for the large number of institutional beds currently in use. An added benefit of directing the state focus toward community living will be long term cost effectiveness. Currently, the average cost for housing a client in a state institution is approximately $69,000 per client per year. Costs associated with community ICF/MR programs are approximately $34,000 per client per year.

C. Budget and Funding Issues

The Task Force studied the varying funding sources available for mentally retarded and developmentally disabled individuals. Topics ranged from established funding sources to the projected Home and Community Based Services (HCBS) waiver. Both institutional and community funding sources were reviewed. Funding for adults and children were equally evaluated.

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Background

Funding for the three state mental retardation institutions, Parsons, Winfield, KNI, totals $70,663,143 in actual expenditures for FY 1990 and $73,236,654 in estimated expenditures for 1991. The General Fund portion of total expenditures is $32,819,827 for FY 1990 and $31,952,394 for FY 199 funding for FY 1990 totals $25,870,986 for all funds including $6,069,996 for state aid, $7,460,9 ommunity purpose grants, $10,350,340 for community/day living, and $1,989,760 for HCBS-MR. Of the special $15,580,002 was appropriated from the State General Fund. For FY 1991, $34,969,161 was approved mount, including $5,963,771 for state aid, $11,872,794 for special purpose grants, $10,350,340 for communi unds, and $6,782,256 for HCBS-MR. Of the total amount for FY 1991, $21,923,275 is from the State Ge ing, d.

Task Force Activity

The Task Force received written and oral testimony from staff, several conferees from MHI community providers regarding major sources of funding for state mental retardation services. The Tas learned that the three state mental retardation institutions receive funding from several sources. Major s of funding include the state general fund, federal Medicaid funds (Title XIX), institution fee funds, federal Ch I, and other federal education funds. To receive federal Medicaid funding, the institutions must comply federal standards and be annually certified. Daily rates are developed annually for each institution reimbursement for clients eligible for Medicaid funding. Almost all of the clients at the mental retardatio institutions are Medicaid-eligible. Of the total rate developed for each institution, the federal Medicaid program pays approximately 57 percent and the state pays 43 percent. Federal Medicaid matching rates are changed at the start of each federal fiscal year (October 1). The federal matching rate is 57.35 percent for FFY 1991 and projected to be 59.23 percent for FFY 1992.

All Kansas ICF/MR programs (public or private, institutions and community programs alike) receive funding through the Title XIX Medicaid program. For a state to receive federal assistance under the Medicaid Act, it must provide payment to ICF/MR providers which is sufficient to cover costs incurred by efficiently and economically operated programs in order to provide care and services in conformity with applicable state and federal laws, regulations, and quality and safety standards. States must also assure that individuals who are eligible for Medicaid have reasonable access to services of adequate quality.

The Home and Community Based Services (HCBS) waiver is an alternative funding source which also utilizes the 43 percent, 57 percent federal match rate. The "waiver" is so called because it waives the ICF/MR guidelines. It is more individualized and can serve individuals in home, apartment, group home settings, community sheltered environment, etc.

In 1981 Congress authorized the first legislation that allowed states to waive certain requirements for long-term institutional care and still receive Medicaid money for services which occurred instead of institutional care. Intermediate care facilities for the mentally retarded (ICFs/MR) were included in this legislation. This allowed states to provide home and community-based services to individuals who were eligible for ICF/MR level of care. Such "HCBS waivers" permitted states to both deinstitutionalize and divert new admissions to ICFs/MR.

States were required to assure the federal Department of Health and Human Services that the per capita cost to provide waiver services would not exceed the per capita cost of providing institutional care. Initially, states could exercise a great deal of flexibility in how they provided waiver services so long as they met basic assurances concerning health and safety, freedom of choice, eligibility, and reporting requirements. Services that can be offered under a waiver include: case management, habilitation, 24-hour supervision group home services, other residential services with a supervision component; prevocational and supported employment services; nonmedical transportation; respite care; adaptations to the home; home health aide; personal care services; and homemaker services.

Initial waiver requests are granted for a three-year period; renewals are generally granted for five-year periods. A waiver can be amended at any time a state wishes to change services or eligibility. The Health Care Finance Administration (HCFA) scrutinizes every waiver submission.

Currently, 41 states now operate regular waivers serving MR/DD clients. Waiver spending for federal fiscal year 1988 was $450.1 million. The total number of persons receiving waiver services was 29,446. The average annual per capita cost was $15,285.

Kansas currently has one waiver. It is expected that the new HCBS waiver will be approved in January or February. If it is approved, up to 1,000 new slots are possible.

Conclusions and Recommendations

Throughout the testimony heard by the Task Force, a reoccurring issue arose regarding the legislative decision making process. Concern was expressed that recommendations regarding the budgets of the three mental retardation hospitals, the four mental health hospitals and SRS are all made independently without one legislative body retaining oversight. Oversight is particularly necessary when one subcommittee is making a recommendation that affects another subcommittee. This was illustrated during the 1990 Legislative Session when a recommendation was made by the House Appropriations mental retardation subcommittee to close a unit at Winfield State Hospital and use the dollars saved at Winfield to fund additional community slots. This recommendation could not be completely implemented since the House Appropriations SRS subcommittee, not the Winfield subcommittee, was responsible for making a recommendation on community funding. Although the subcommittees coordinated their decisions as closely as possible, the full Committee heard each subcommittee's recommendation at a different time.

The Task Force notes with concern that no one entity reviews the "big picture" detailing the crossover between community and institutional funding. The Task Force recommends that the House Appropriations Committee and the Senate Ways and Means Committee review the current policy of assigning multiple subcommittees to make related budget decisions. The Task Force further recommends that one subcommittee review all seven hospitals' budgets and the Mental Health and Retardation services portion of the SRS budget. In the alternative, the Task Force recommends that subcommittees reviewing the mental health and mental retardation hospitals budgets conduct joint meetings with the SRS subcommittee to establish a continuity in funding recommendations for these agencies.

In conjunction with the recommendation that legislative oversight be unified, the Task Force also notes that coordination between the various agencies dealing with mentally retarded and/or developmentally disabled adults and children is critical. The Task Force encourages the Department of Education (special education) to coordinate and communicate with Social and Rehabilitation Services. It is the belief of the Task Force that the key to providing effective services without duplication requires effective communication between state agencies.

D. Commission on Mental Retardation

The Task Force reviewed 1990 H.B. 2578, which was not enacted.

Background

H.B. 2578 would establish a Governor's commission on mental retardation and other developmental disabilities. The commission shall consist of 15 members with one member representing state mental retardation institutions; three members representing the Department of Social and Rehabilitation Services; one member representing Kansas Advocacy and Protective Services for the Developmentally Disabled; three members representing community mental retardation facilities; one member representing the Kansas Association of Rehabilitation Facilities; three members who are family members or advocates of the mentally retarded; one representing intermediate care facilities with more than 15 beds; one representing intermediate care facilities with less than 15 beds; and one member representing the affiliated program of the University of Kansas. Each member shall be appointed by the Governor for a term of two years.

Section 2 of the bill sets out the duties and responsibilities of the Commission. Such duties range from consulting with and advising the Governor regarding management, conduct, and operation of mental retardation institutions and programs to acting as an advocate for mentally retarded citizens.

Conclusions and Recommendations

The Task Force recommends that H.B. 2578 be reintroduced in its final form, *i.e.*, as amended by the House Committee on Appropriations. The Task Force further recommends that Section 2(b) of the bill include a subsection stating that the commission shall identify problem children with special needs and develop a master plan to address those needs. Additionally, the Task Force recommends that the charge of the commission include advocating for long-range transition planning and, in particular, encouraging vocational rehabilitation, and the Department of Education (through special education) to work together.

E. ICF/MR Reimbursement

The Task Force reviewed the Developmental Disabilities Profile and the formula used by the Department of Mental Health and Retardation to set reimbursement levels for ICFs/MR administrative costs.

Background

Until October, 1988 SRS reimbursed ICFs/MR in the same way that it reimbursed nursing facilities. Facilities were reimbursed for the cost of providing services up to limits established for five cost centers. Any facility which exceeded these limits was reimbursed up to the limit of the cost center. Exceptions were made to accommodate exceptional circumstances:

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1. Community Living Opportunities (CLO) was established as a special class of facility based on the assumption that at least 50 percent of its clients were nonambulatory.

2. A provision was established which allowed a facility which was experiencing difficulties with certification an opportunity to increase its reimbursement rates on a projected basis to help correct severe certification deficiencies.

3. New Horizons, Winfield (currently Focus Developmental Center) experienced severe certification difficulties and established as a special class of facility based on the assumption at least 50 percent of its clients are severely or profoundly mentally retarded.

4. Developmental Services of Northwest Kansas (DSNWK) was established as another special class of ICFs/MR when it agreed to serve former Norton State Hospital clients in small community group homes funded as ICFs/MR.

Nearly all of the ICFs/MR claimed to fit into one of the special classes established above. Medicaid policy requires all facilities to be treated in a consistent manner. Therefore, the rates paid to ICFs/MR have increased dramatically regardless of whether the clients served by the facility truly needed the increased services.

All clients in public and private ICFs/MR were screened with the Developmental Disability Profile (DDP). According to MHRS, the DDP is a planning and reimbursement tool. Facilities were grouped into levels and scores were calculated for each client in each facility. These scores were averaged for each facility and combined with the average severity of disability of the clients served by the facility. Based on these statistics with a variety of cross checks, MHRS developed a proposed percentage of direct services to be allowed by the various sizes of facilities.

Task Force Activity

The Task Force received written and oral testimony from SRS regarding proposed changes to the ICFs/MR direct service reimbursement model. SRS proposes to change the reimbursement methodology from percentile limits to one more appropriate for facilities which serve clients with mental retardation and other related conditions. The goal of these proposed changes is to establish a reimbursement method which correlates to the level of independent functioning of the clients served by each ICF/MR facility. As discussed in the background above, SRS allowed several named ICFs/MR to be reimbursed according to client functioning levels. Two examples were CLO and DSNWK. When the Legislature directed the closure of Norton State Hospital it became obvious that some of the more behaviorally involved and severely mentally retarded clients could not be served for the designated amount in small integrated community programs. Therefore, special ICFs/MR were established to handle these clients. The rates for these new bed facilities was approximately $150 per day. The clients in these ICFs/MR were similar in mental retardation to the clients at CLO, however, the clients at CLO did not have the severe maladaptive behaviors seen at DSNWK.

When establishing a rate for the DSNWK homes it was difficult to determine a reasonable amount for indirect administrative overhead for this multi-county organization. It was agreed that DSNWK would be allowed to allocate indirect administrative overhead as a percentage of the direct operational expenses. DSNWK was directed to use this allocation methodology for all of its programs. This procedure allowed these ICFs/MR to allocate central office indirect administrative costs at unprecedented high levels.

SRS was not able to establish and monitor a minimum client disability level to qualify for the reimbursement rates allowed at DSNWK Norton facilities. Therefore, many new and some old ICF/MR providers applied for and received similar rates. In many cases the clients served by these programs were far less disabled than the clients served by CLO and DSNWK.

According to SRS, these circumstances have driven the cost of the ICF/MR program up substantially in the last several years. The cost of the ICF/MR program has increased more than 76 percent while the number of clients served has increased by 10 percent. Therefore, SRS is proposing to reimburse ICFs/MR based on rates related to the level of independent functioning of the clients served in each facility rather than the type of facility itself.

To obtain the necessary information, every client in ICFs/MR in Kansas, including those in state MR hospitals, were screened using the DDP. Scores obtained (which include adaptive behavior, maladaptive behavior, and health needs) were analyzed and facilities were ranked according to converted scores and then divided into groups. The agency then proposed direct service levels for a reimbursement methodology. The levels differentiate between three classes of facilities on the basis of size. These facility size classes are 4-8 beds; 9-16 beds, and 17+ beds.

SRS states that the direct service reimbursement methodology is the foundation of the proposed ICF/MR reimbursement system. The common sense principle underlying the direct service methodology is the relationship between the level of disability of the person served and the number of direct service staff needed. (administrative reimbursement structure).

SRS proposes that the per diem limit reimbursement for facility ownership be based on the historic cost of each facility. It is assumed that these costs are based on long term commitments made by agencies and should not be limited below that which they are already incurring.

SRS further proposes that plant operating per diem expenses be limited based on the average cost of plant operating for each size of facility.

The Task Force also heard from community providers regarding the reimbursement of ICFs/MR costs. The gist of the testimony is that some of the SRS basic philosophy is sound, particularly that philosophy which pays higher rates for those with greater needs than those with lesser needs. Additionally, some degree of recognition was given to facility size, in an attempt to reward programs that are serving people with greater needs in small community group homes. While philosophically sound, the outcomes produced by the plan would be devastating for all community programs. The rate produced by the mechanics of the plan were far below what is needed to provide minimum care. Some facility budgets would be slashed 50 to 60 percent. Although some facilities may receive a slight increase, most facilities would be cut. The result of most cuts would force providers to make hard decisions to close some homes and/or discharge some Medicaid-eligible clients. Due to the public outcry regarding the proposed plan, Dennis Taylor, Secretary of Social and Rehabilitation Services, authorized a delay in implementing the changes. The Director of Mental Retardation also began working with the providers in a series of meetings.

It is the Task Force's understanding that SRS is attempting to work with the providers to reach a reasonable compromise on reimbursement issues. The Task Force learned that MHRS and various representatives of ICF/MR providers, parents, and non-ICF/MR providers have now met four times, the last meeting taking place on December 13, 1990. To date, agreements have been reached on the following issues:

1. Two models for setting limits on reimbursement in four areas (a) Administration; (b) Owner costs; (c) Plant Operating Costs; and (d) Direct Service have been chosen. These models have been distributed to all ICFs/MR to enable them to determine the effect on current practices. It is the agency's hope that a final agreement on a single model will be adopted at a meeting scheduled for January 9, 1990.

2. Policies which will facilitate understanding and implementation of the reimbursement process have been drafted, revised, and distributed. They too, hopefully will be finalized at the January meeting.

3. Upon finalization of the model, the parties recommend a phase-in process that encompasses FY 1991 and FY 1992. Current appropriation requests and supplemental appeals will allow implementation of this new system without harm to clients while enabling providers to accomplish

this within requested appropriations. It was agreed that rates will remain as they currently are for FY 1991 until the new funding mechanism can be implemented.

Conclusions and Recommendations

The Task Force notes with concern the apparent conflict between the community providers and the Division of Mental Health and Retardation Services. The Task Force is pleased to learn that MHRS and the providers are holding public meetings to attempt to reconcile their differences. The Task Force recommends that a strict formula of reimbursement for ICFs/MR be developed and commends MHRS and the community providers for their efforts to work together to solve their differences.

F. Family Support

The Task Force reviewed issues related to disabled children including guardianship proceedings, special education, and vocational training, family support, and family subsidy.

Background

Until recently, parents of children with disabilities were faced with only two service choices -- they could provide care at home with little or no external support, or they could forego traditional parental functions by placing their child outside of the family home, usually in an institutional setting. A third option, however, is slowly evolving. In many states families can provide care at home, and receive services to support their efforts and enhance their caregiving capacity.

This "support not supplant" theory brought about a new interest in the development of services for people with disabilities within the family homes. On the federal level, the terms "family support," family centered," and "community based" became common. This was accompanied by the development of a variety of new federal programs which were specifically designed to provide for services to people with disabilities within the family home.

No two families or two persons with disabilities are exactly alike. This means that the type of support a family may need can differ from those needed by other families. This has led many to conclude that the "support" in family support should be defined by the family. As such, a family support program must be prepared to provide whatever it takes to maintain and enhance the family's capability to provide care at home.

Family support is usually not construed as a single service, but rather as a flexible and varied network of supports that can accommodate individual family concerns. Types of services provided by states include respite care, cash subsidies, purchase of adaptive equipment, family counseling, occupational therapy, parent training, physical therapy, behavior management, case management, speech therapy, home or vehicle modifications, transportation, homemaker services, medical/dental care, skill training, attendant care, evaluation or assessment, home health care, child care, special clothing, recreation, discretionary cash, family support groups, nursing services, information and referral, sitter services, advocacy, camps, utility payments, chores, health insurance, home repairs, rent assistance, and other services.

Kansas is one of nine states that does not have specific statewide family support initiatives. The publication, *Family Support Services In the United States: An End of Decade Status Report*, written by the Human Services Research Institute (February, 1990) lists Kansas last among the 50 states in the family support effort.

Task Force Activity

The Task Force heard testimony from a variety of conferees and staff concerning family support and family subsidy issues. The Task Force focused on the three states (Wisconsin, Michigan, and Minnesota) which have comprehensive family support legislation. Eligibility requirements vary with each state: Michigan legislation is directed toward children with developmental disability based on need determined by the Community Mental Health Boards. The cash subsidy is directed toward families with children between the ages of 0-18. Children must be classified as Severely Mentally Impaired, Severely Multiply Impaired, or Autistic Impaired. The child must live at home with the natural or adoptive parents. The family's taxable income cannot exceed $60,000. Minnesota limits its program to families whose dependents are under the age of 22, and who are mentally retarded or have a related condition and otherwise would require or be eligible for placement in a licensed residential facility. Wisconsin also requires that the child be between the ages of 0-21, have a developmental disability, and live with his/her natural or adoptive family. All three programs have a maximum subsidy amount of $3,000 ($250 per month) per family.

The Task Force also reviewed 1990 H.B. 3075 (not enacted) which attempted to establish a family support subsidy program in Kansas. The bill provides that the program shall be limited to families with dependents under the age of 22 years and who are mentally retarded or who have a related condition. The child must be eligible for placement in a residential facility.

The bill provides that a transitional plan shall be developed for the dependent when the dependent becomes age 17 in order to assure an orderly transition to other services when the family is no longer in the subsidy program.

Subsidy amounts shall be determined by the Secretary of SRS and shall not exceed $250 a month. Emergency funds may be available at the discretion of the Secretary.

In addition to receiving information on family support, the Task Force also heard testimony from several conferees regarding a variety of family issues. Conferees testified about guardianship issues, the increase of special education students in the state school system, vocational rehabilitation, and disabled parents with environmentally disabled children.

Conclusions and Recommendations

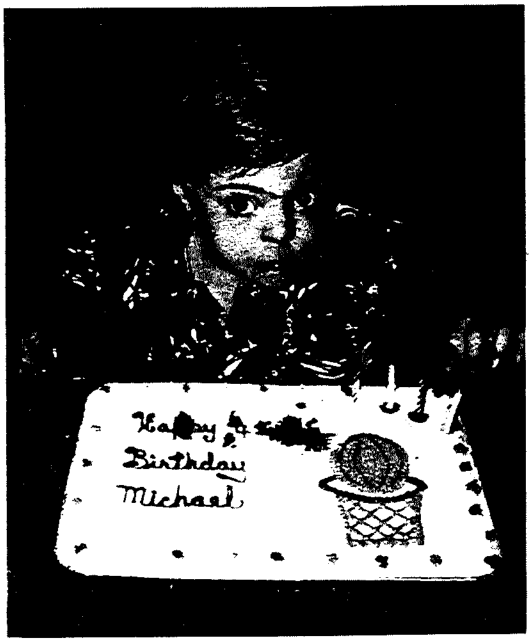
The Task Force recommends legislation implementing a pilot family support system in Kansas. The Task Force learned that few community ICFs/MR or group homes accept children; therefore, when a crisis situation arises, the child is often institutionalized. The Task Force believes that institutionalization may be avoided if respite or other types of support services are available. The Task Force recommends that that family subsidy be a component of the legislation. Other services or goods that could be included are: (1) architectural modifications to the home; (2) child care (3) counseling and therapeutic resources; (4) dental and medical care not otherwise covered; (5) specialized diagnosis and evaluation; (6) specialized nutrition and clothing; (7) specialized equipment and supplies; (8) homemaker services; (9) in home nursing and attendant care; (10) home training and parent courses; (11) recreation and alternative activities; (12) respite care; (13) transportation; (14) specialized utility costs; and (15) vehicle modifications. Additionally, the program should have the flexibility to pay for the costs of other goods or services approved by the state.

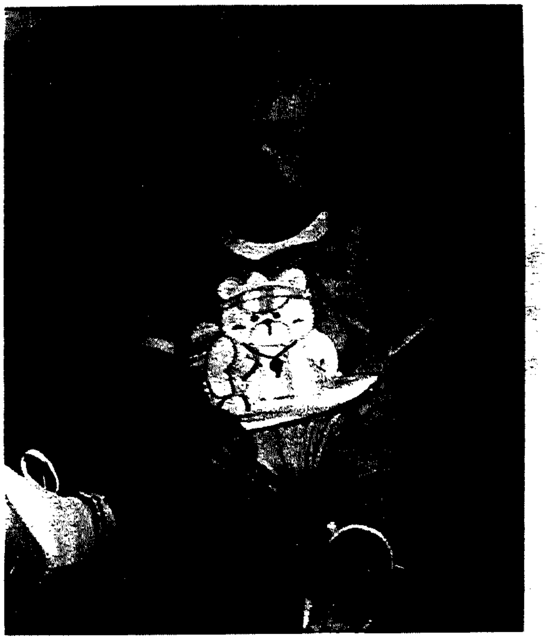
The Task Force further recommends that the pilot program should be limited to 200 families or less, with a $3,000 limit per year, per family. The program would be limited by conditions subject to appropriations.

The Task Force views the pilot project as a demonstration of the family support system. The Task Force recommends that the Department of Social and Rehabilitation Services report back to the Legislature on the status of the pilot project.

Mental Health and Retardation Services
Division of Mental Retardation/Developmental Disabilities

THE KANSAS FAMILY SUBSIDY PROGRAM





KANSAS DEPARTMENT OF SOCIAL AND REHABILITATION SERVICES

> SRS Mission Statement
>
> "The Kansas Department of Social and Rehabilitation Services empowers individuals and families to achieve and sustain independence and to participate in the rights, responsibilities and benefits of full citizenship by creating conditions and opportunities for change, by advocating for human dignity and worth, and by providing care, safety and support in collaboration with others."

October, 1994

House Select Committee on
Developmental Disabilities
2-8-95
Attachment 2-

2-1

"The family is the nucleus of civilization."
Will and Ariel Durant

Thanks to all the families who completed surveys and made this report possible.

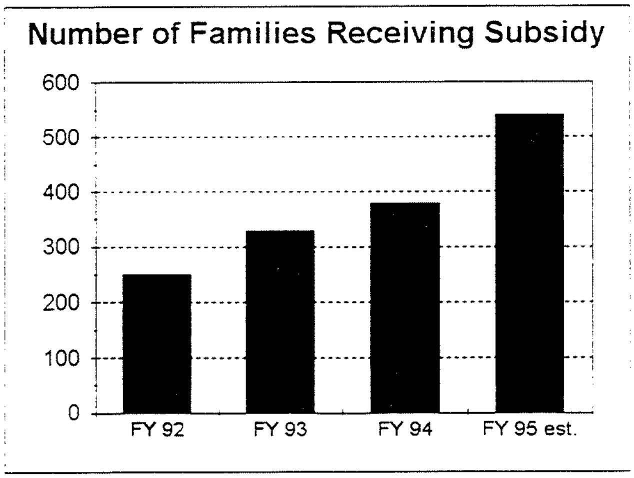
2-2

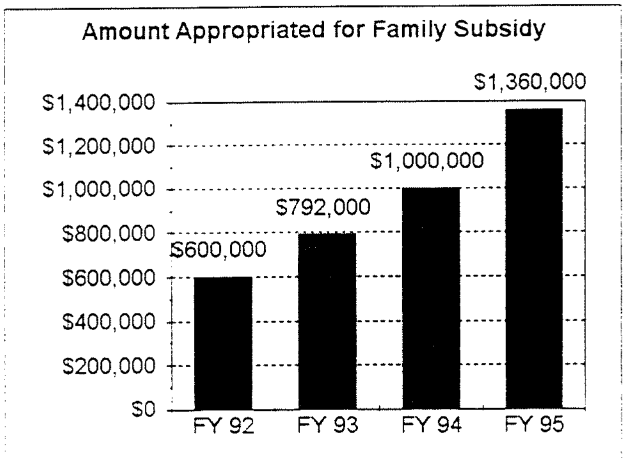
e 1991 Kansas Legislature authorized SRS to pilot a family subsidy program using $600,000. Family subsidy is direct cash assistance to families with one or more children with developmental disabilities. Its intent is to help families meet the extraordinary expenses necessary in caring for children in their own home and in the community in which they live. The decisions about how to use subsidy funds are made by the parents. The subsidy may be used for anything the family needs.

The birth of a child with a disability often creates service and financial challenges for a family. Historically, extra effort and expense have forced many families to face it alone, or to place their child in a service system geared to institutional care in segregated facilities. Exclusion from the mainstream of community life and separation of the family was a part of this process. Family subsidy is meant to assist families in meeting demands of care[1] by embracing family centered care.[2] Subsidy is thought to reduce family stress, increase the family's ability to cope, and to improve quality of life and satisfaction.[3,4] Eighteen states operated subsidy programs in 1992, serving a total of 12,431 families.[5] Michigan's program is the largest, serving 3,922 families at a cost of $10,414,137. Its program has been used as a model across the country.

In Kansas, families may apply throughout the year for the subsidy; if they meet the income and disability requirements, they are eligible for random selection as more funds become available. Once a child reaches age 18, his family may no longer receive subsidy, and another family is selected. The eligibility requirements and some administrative procedures were determined with input from the SRS Division of Mental Retardation/Developmental Disabilities Services and a Family Advisory Council. These requirements are outlined in the application in Appendix A.

Since the 1991 legislative session, the subsidy program has increased each year. The graphs below illustrate the growth in the number of families served and the amount appropriated each year.

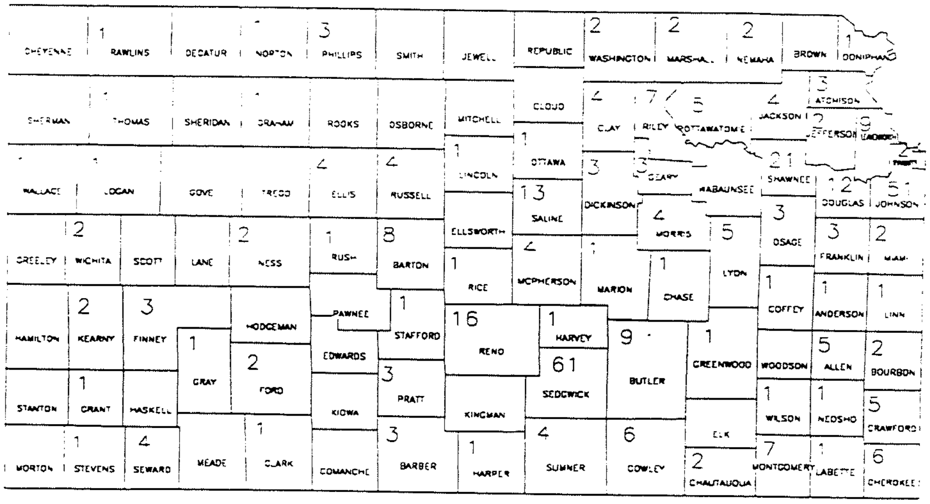




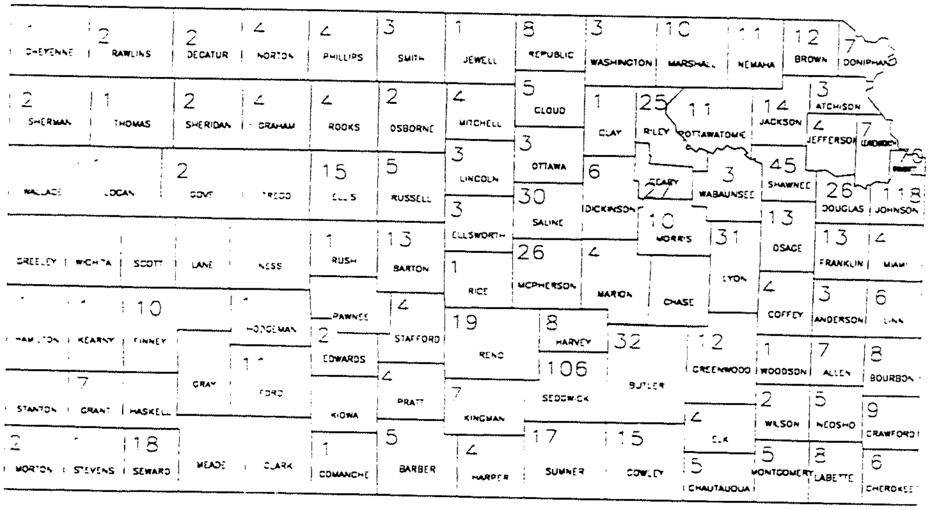
Since the beginning of the program 1,668 families have applied. Three hundred and eleven families were determined ineligible or were removed from the program after their child turned 18, or accessed other services. Currently 378 families are receiving subsidy, with an additional 125 to be added in January. Application forms are disseminated through SRS offices, health departments, school districts, and community mental retardation agencies. Initially 10,000 brochures with applications were mailed. The program is kept relatively simple to make it "family friendly", and none of the funds appropriated are used to administer the program. This allows as many families as possible to be served. Families receive $200 per month, paid quarterly.

The maps below show from which counties applications have been received and the number of families in each county who currently receive subsidy payments.

NUMBER OF FAMILIES RECEIVING FAMILY SUBSIDY

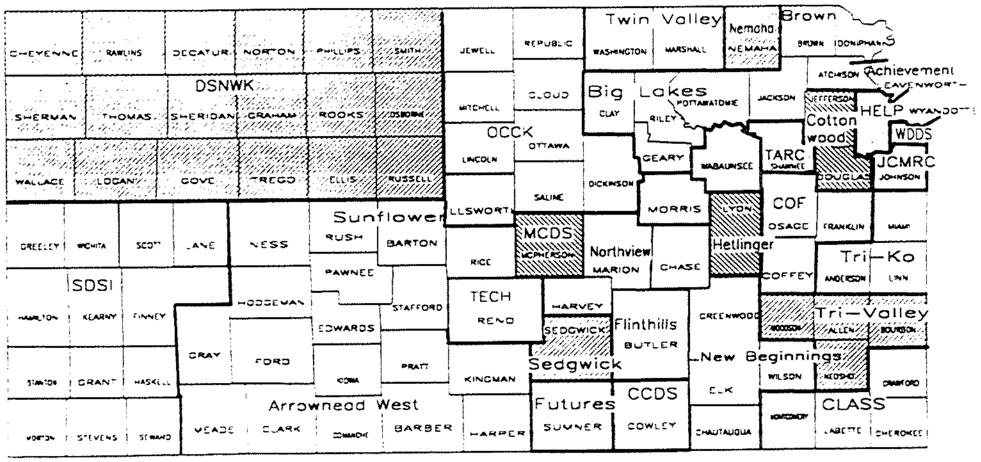


NUMBER OF FAMILIES WAITING FOR FAMILY SUBSIDY



To ensure the program is truly statewide, the Family Advisory Council recommended that families be randomly selected from community mental retardation center regions (see map below) of the state based on percentage of total population. The counties not served by a community mental retardation center are treated as an additional region based on percentage of statewide population. Iowa uses a similar process for its subsidy program.[6]

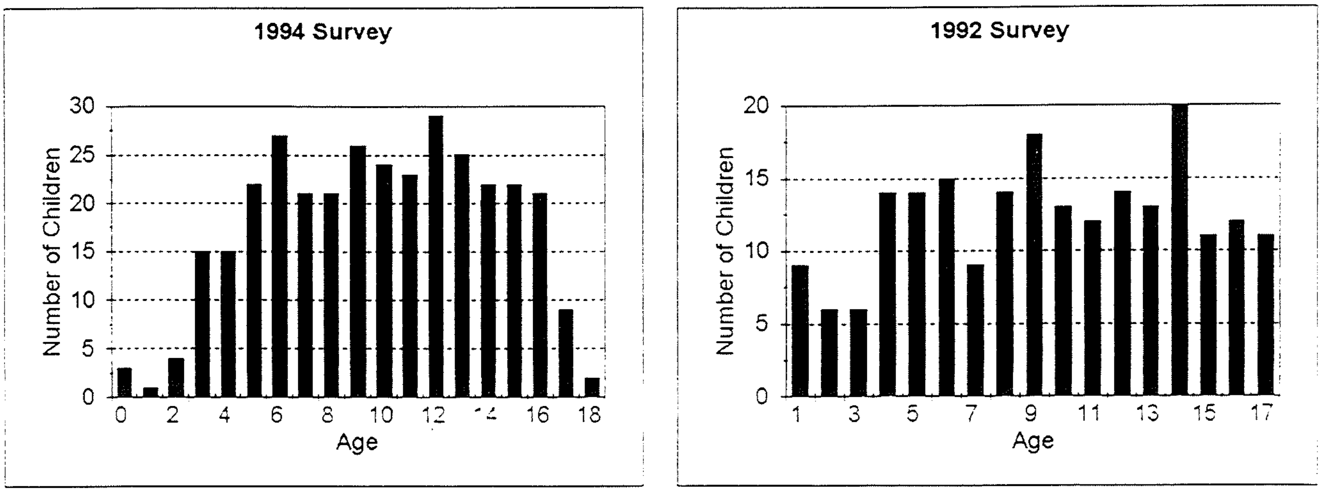
Community Mental Retardation Centers of Kansas



In January, 1994, a survey (included in Appendix B) was mailed to all families who were receiving subsidy payments (390). Three hundred thirty-five surveys were returned (85.9%) - a phenomenal return rate for a survey. In keeping with the simplicity of the program and its minimal intrusiveness, the survey was brief, asking for age of the child, family income level, county of residence, and how subsidy was spent. In addition there were questions about what families liked most, and least, about the program and how it could be improved. The question concerning special education category was not analyzed because many families misunderstood it.

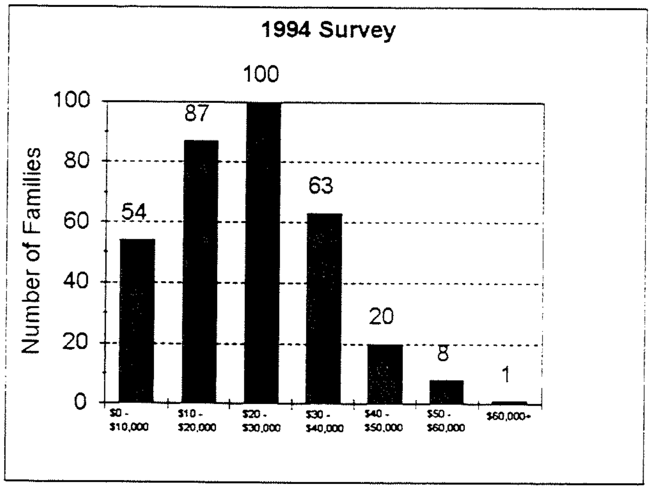
The vast majority of children whose families receive subsidy are in the 5-16 years old age range - 84.5% (283). Less than one percent are under one year of age. The average (mean) age of all children whose families returned surveys is 9.8 years. An earlier survey, conducted in July 1992, revealed an average age of 11.7 years. One hundred and seventy-one families responded to the earlier survey.

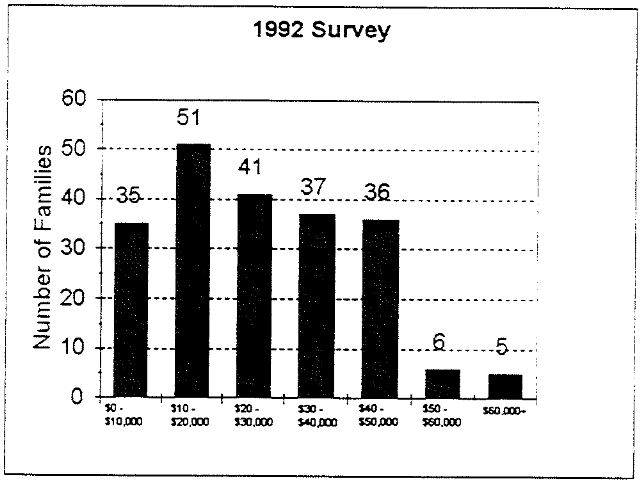
AGE OF CHILDREN SERVED IN FAMILY SUBSIDY



Information about income indicates family subsidy serves primarily lower and middle income families. One hundred families (29.8%) reported net incomes between $20,000 and $30,000; eighty-seven (26.1%) reported net incomes between $10,000 and $20,000. The 1992 survey demonstrated a similar distribution of income with 24.2% of families reporting income in the $10,000 to $20,000 range, and 19.4% reporting income between $20,000 and $30,000.

INCOME OF FAMILIES RECEIVING SUBSIDY


1994 Survey


1992 Survey

It appears that family income distribution in the four most populous counties essentially reflects the distribution as a whole for the most recent survey, however, Sedgwick and Wyandotte counties do show more families in the lowest income range than the state as a whole - as would be expected.

INCOME RANGES FOR JOHNSON, SEDGWICK, SHAWNEE, AND WYANDOTTE COUNTIES
1994 Survey

	# FAMILIES REPORTING INCOME RANGE						
COUNTY	$0 to $10,000	$10,000 to $20,000	$20,000 to $30,000	$30,000 to $40,000	$40,000 to $50,000	$50,000 to $60,000	$60,000 +
Johnson	5	7	12	10	4	3	0
Sedgwick	11	10	13	9	2	1	0
Shawnee	2	7	10	3	0	0	0
Wyandotte	6	4	5	3	3	0	0
Totals	24	28	40	25	9	4	0

2-6

ilies were given a list of equipment, items, and services and asked to mark those which they purchased with subsidy. The most frequently marked expenses in the 1994 survey were medical expenses, clothing, general expenses, and diapers. The tables below detail each expense category and the number of families which marked it in each survey.

EXPENSES OF FAMILIES **(1994 Survey Results)**		
Expense	No. Families	%
Purchase special equipment	84	25.1
Home modification/renovation	26	7.8
Van lift	3	0.9
Respite care purchased from an agency	18	5.4
Respite care purchased from individuals	43	12.8
Camp for the child with a disability	34	10.1
Care for other children	23	6.9
Medical expenses	215	64.2
Therapy (physical, occupational, or speech)	45	13.4
Clothing	204	60.1
Diapers	124	37
Special foods/nutritional supplements	69	20.1
Home nursing care	4	1.2
Attendant care	20	6.1
Transportation	102	30.4
Counseling/behavior management	25	7.5
Educational aids	114	34
General household expenses	151	45.1
Medical insurance	53	15.8
Other	49	14.6
Note: Families were instructed to mark up to five items/services so percentages will not add up to 100.		

EXPENSES OF FAMILIES **(1992 Survey Results)**		
Expense	No. Families	%
Adaptive Equipment	47	27.5
Camp	9	6.3
Care for other children	16	9.4
Clothing	54	31.6
Community activity, participation, recreation	43	25.1
Computer	10	5.8
Counseling/Behavior Management	6	3.5
Diapers	27	15.8
Educational Aides	31	18.1
Food (incl. special foods)	36	21.1
Home Nursing Care	0	0
Home Renovation	4	2.3
Household	34	19.9
Medical (dental, pharmacy, hospital, insurance)	85	49.7
Therapy (PT, OT, Speech, augmentative)	13	7.6
Respite	13	7.6
Sitters	11	6.4
Supportive Home Care	0	0
Transportation	28	16.4
Other	3	1.8

Regardless of income level, medical expenses and purchase of clothing were primary uses of subsidy for families. With the exception of the two highest ranges, families in all other income levels also listed paying general expenses as a way subsidy was primarily used. The table below details how many families at each income level spent subsidy money on each expense.

FAMILY EXPENSES BY INCOME LEVEL - 1994 SURVEY

	Expenses																			
INCOME RANGE	Special Equipment	Home Modification	Van Lift	Respite/ Agency	Respite/ individual	Camp	Care for other children	Medical	Therapy	Clothing	Diapers	Special food	Nursing care	Attendant care	Transporta-tion	Counseling	Educational Aids	General expenses	Medical insurance	Other
$0 to $10,000	7	5	0	0	5	4	4	16	3	45	21	17	1	5	29	3	21	35	10	11
$10,000 to $20,000	16	5	1	2	10	5	5	54	11	58	34	17	0	5	39	7	27	57	11	9
$20,000 to $30,000	26	9	0	3	11	10	7	78	15	57	41	17	1	5	20	8	33	36	18	18
$30,000 to $40,000	25	2	0	9	9	12	5	48	9	30	19	14	1	4	9	5	21	19	12	8
$40,000 to $50,000	8	3	1	4	5	2	1	14	4	9	6	4	1	0	1	1	9	2	1	1
$50,000 to $60,000	1	2	1	0	2	1	0	4	3	4	2	0	0	1	3	1	2	0	1	1
$60,000 -	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1

2-7

Three open-ended questions were also asked:

1. What do you like **most** about Family Subsidy?
2. What do you like **least** about Family Subsidy?
3. What suggestions do you have to improve Family Subsidy?

Since the responses tended to fall into several naturally occurring categories, they were grouped that way for data entry. The most frequently occurring comments regarding what families liked most had to do with flexibility. That subsidy payments are not earmarked for any specific expense was listed by 94% (315) of the families as what they liked most about the program. Some typical comments were:

> *I like the fact that the money can be spent on anything. A lot of normal families don't realize how hard it is financially having a "special child" to take care of and raise.*
>
> *That the money is to be spent as needed and where needed - also that we don't have to account for every dollar spent and where the money went - like SSI does.*
>
> *The fact that I have discretion regarding the use of the funds. Our needs fluctuate and change and I can easily adapt to that with the subsidy sent to me as it is.*

Many families told us specifically how family subsidy has helped them:

> *The assistance we receive for our daughter helps our family. We have had many hardships financially and emotionally. We have had many medical expenses throughout the years. When we did not receive assistance it was very hard to meet our finances. We have always tried to give her all the therapy she has needed ever since she was an infant, it was very expensive but we continued to try and help her even if we were in debt. It is important to us that she live as normal a life as possible. Our other children have had to do without many things including dental work they have needed. And if another family member were to need medical assistance it would cause more financial hardship. This program helps take away some of the pressure.*
>
> *Family Subsidy has been such a blessing to our family. Since my daughter was 8 months old, I haven't been able to work, so we only had my husband's income and SSI. From month to month we could barely make ends meet. It was bad enough to move down, as far as quality of life, but we felt we would never be able to move ahead even a little. Subsidy has taken off so much pressure. I feel families with a disabled child have enough pressure to hold things together, even without financial troubles. Thank whoever deserves the credit for Kansas Subsidy from our entire family.*
>
> *It has enabled us to do more for our child that we could not have done before. For example -- we used part of it for car repairs and later to help to purchase a more dependable car after our old one completely gave out. We make <u>frequent</u> trips to Kansas City for medical care and need <u>dependable</u> transportation. This enabled us*

> *to keep up on that without having to stretch ourselves more on an already stretched budget.*

What families liked **least** about the program included quarterly (rather than monthly payments), the subsidy amount not being high enough, that more families cannot be helped, not knowing how long the program will last, that checks are not mailed on the same date each quarter, and that eligibility ends at age 18. The majority of families, however, (68.96%) indicated there was nothing they liked least about the program. One family wrote, "What's not to like? It's a Godsend!"

Suggestions for improvement mirrored what families liked least: extending eligibility past age 18, helping more families, paying monthly, paying more money to each family, and mailing checks on the same date. Again, the majority of families (60.9% indicated there was no need for improvement.

> *We have not had any problems and it has saved us alot of headache and expense when trying to come up with extra money for these much needed services. We appreciate it more than you will ever know. Thank you!!*
>
> *Just to continue it. We appreciate it very much.*
>
> *I have no suggestions to improve it. I just hope that it stays in the budget. Alot of families who are receiving it such as ours really are in need of it. We have no savings so we have nothing to fall back on at least this subsidy is there so we can meet those expenses for our son. Thank you!*
>
> *I believe you are doing a very good job. I hope you know how grateful and thankful we are for your help. There are times when we would go without food, or laundry detergent, soap etc. if it weren't for your generosity and help.*
>
> *None at this time. Of all the programs in place this one (Family Subsidy) is surely the program with the least amount of red tape and the easiest to administrate. Thank you for a program that gets the needs met with minimal amount of paperwork. Family Subsidy has helped us tremendously.*

Clearly, the family subsidy program is exceptionally popular. With a relatively small amount of money, over 400 Kansas families are being helped. The simplicity and flexibility of the program make it possible for families to decide how best to use the money to meet the needs of their children. This program illustrates how families can be empowered when they control the decisions about how and where to spend the money provided to them, and is consistent with values of choice and person-centeredness outlined in the SRS MRDD Services five year plan, **Supporting Kansans with Developmental Disabilities**.

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2. Taylor, S.J., Knoll, J.A., Lehr, S., & Walker, P.M. (1989). Families for all children: value based services for children with disabilities & their families, in Singer & Irvin, Ibid.

3. Meyers, J.C. and Marchenko, M.O., Impact of a cash subsidy program for families of children with severe developmental disabilities, **Mental Retardation** (1983), **27**, 383-386.

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5. Braddock, D., Hemp, R., Bachelder, L., & Fujiura, G. (1994). **The state of the states in developmental disabilities: Fourth national study of public spending for mental retardation and developmental disabilities in the United States**. Draft report from Institute on Disability and Human Development: University of Chicago.

6. 59 Illinois Administrative Code, Chapter 1, 117.120.

APPENDIX

A

FAMILY SUBSIDY
CASH PAYMENTS
TO FAMILIES
FOR CHILDREN WITH MR/DD

Family Subsidy is a program designed to provide cash payment to families with a child that is mentally retarded or otherwise developmentally disabled (MR/DD) and lives at home. The cash payment is $200 a month, paid every three months.

Effects Family Subsidy has on other programs:

1. Supplemental Security Income (SSI) - has no effect.
2. Aid to Families with Dependent Children (AFDC) - has no effect.
3. Food Stamps - has no effect.
4. HUD Housing - it is considered when figuring income.
5. HCBS/MR - cannot receive in addition to Family Subsidy.
6. ACIL - cannot receive in addition to Family Subsidy.
7. You cannot receive services funded by MH&RS in addition to Family Subsidy.

Families are required to submit an application. If they meet all the requirements, they will be assigned a random number by regional area. The state is divided into areas in which the Community Mental Retardation Centers (CMRCs) are responsible for providing services. Slots are then allocated to these areas based on the population of that area.

Requirements for this program are as follows:

1. Child must be 17 years of age or less, AND
2. Family income must be less than $65,000 a year, AND
3. Child must be living with natural or adoptive parent, AND
4. Child must meet the definition of MR/DD.

If your child meets all of the above requirements, complete and return the enclosed application along with verification of your income.

If you have any questions, please contact Rita Hodges at (913) 296-3476.

DEFINITION OF MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES

Mental retardation means significantly sub-average intellectual functioning as evidenced by an IQ score of 70 or below on a standardized measure of intelligence. Other developmental disability means a condition such as autism, cerebral palsy, epilepsy, or other similar physical or mental impairment. In addition, **mental retardation and otherwise developmentally disabled** is evidenced by a severe, chronic disability which:

1. is attributable to a mental or physical impairment or a combination of mental and physical impairments, AND

2. is manifest before the age of 22, AND

3. is likely to continue indefinitely, AND

4. results in substantial functional limitations in any three or more of the following areas of life functioning:

    a. self-care,

    b. understanding and the use of language,

    c. learning and adapting,

    d. mobility,

    e. self-direction in setting goals and undertaking activities to accomplish those goals,

    f. living independently,

    g. economic self-sufficiency, AND

5. reflects a need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are lifelong, or extended in duration and are individually planned and coordinated, AND

6. does not include individuals who are solely severely emotionally disturbed or seriously and persistently mentally ill or have disabilities solely as a result of infirmities of aging.

DIRECT FAMILY SUBSIDY APPLICATION

1. Head of Household: (Payment will be made to this person.)

Last Name	First Name

2. Spouse:	Last Name	First Name

3. Mailing Address:	Street or Box Number	City	State	County	Zip Code

4. Name(s) of the family member(s) who are mentally retarded or otherwise developmentally disabled and how they are related to #1 or #2.
NOTE: Your child must be 17 years of age or younger to qualify.

Last Name	First Name	SS#	Birthdate MDY	Age	Relationship
Last Name	First Name	SS#	Birthdate MDY	Age	Relationship

5. List the combined adjusted gross family income: $

Enclose a copy of page 1 of your most recent federal tax return or some other verification of income.

	Yes	No
6. The family member(s) who is mentally retarded or otherwise developmentally disabled lives in my home and/or is declared by me as a dependent on my federal income taxes.		
7. The family member(s) who lives with me are mentally retarded or otherwise developmentally disabled. (See attached definition):		

If your family is chosen, you will be required to submit documentation to show that your child meets the attached definition of MR/DD.

	Yes	No
8. Are you willing to forgo any financial assistance that you receive from other state-funded programs.		
9. Has the family member been determined eligible for Supplemental Security Income (SSI) or Social Security Disability Income (SSDI)? If so, how much SSI/SSDI is received monthly? $__________ (SSI) $__________ (SSDI)		
10. I authorize MH&RS to release information about me to Families Together, Assoc. for Retarded Citizens, local Community Mental Retardation Center or other family advocacy groups:		

I assure that the information contained in this application is complete and accurate.

Signature	Phone # (during day)	Date

Return all applications to: Mental Health and Retardation Services, Family Subsidy Program , 915 Harrison - 5th Floor, Topeka, KS 66612-1570.

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APPENDIX

B

FAMILY SUBSIDY RECIPIENT SURVEY
1994

1. How old is the child for whom you receive subsidy? _____

2. What county do you live in? ______________________

3. Which category best reflects your annual family net(after taxes) income?

a._____0 - $10,000
b._____$10,000 - $20,000
c._____$20,000 - $30,000
d._____$30,000 - $40,000
e._____$40,000 - $50,000
f._____$50,000 - $60,000
g._____$60,000 and over

4. Mark the items listed below for which your family most frequently used family subsidy. Mark the item most frequently obtained with a "1", the next most frequent with a "2" etc. Mark only five or fewer items.

a._____purchase special equipment
b._____home modification/renovation
c._____van lift
d._____respite care purchased from an agency
e._____respite care purchased from individuals
f._____camp for the child with a disability
g._____care for other children
h._____medical expenses
i._____therapy (physical, occupational, or speech)
j._____clothing
k._____diapers
l._____special foods/nutritional supplements
m._____home nursing care
n._____attendant care
o._____transportation
p._____counseling/behavior management
q._____educational aids
r._____general household expenses
s._____medical insurance
t._____other

5. What **special education category** has your child been assigned? (Check all that apply.)

a._____autism (AU)
b._____behavior disorder (BD)
c._____deaf-blind (DB)
d._____developmental delay (DD)
e._____early childhood (EC)
f._____educable mental retardation (EM)
g._____hearing impaired (HI)
h._____interpreter svcs (IN)
i._____learning disabled (LD)
j._____mobility assistance (MA)
k._____other hlth impaired (OH)
l._____occup. therapy (OT)
m._____physically impaired (PI)
n._____physical therapy (PT)
o._____speech language (SL)
p._____severe multiple disability (SM)
q._____traumatic brain injury (TB)
r._____trainable mental retardation (TM)
s._____visually impaired (VI)

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6. What do you like **most** about Family Subsidy?

7. What do you like **least** about Family Subsidy?

8. What suggestions do you have to improve Family Subsidy?

BILL GRAVES, GOVERNOR OF THE STATE OF KANSAS

KANSAS DEPARTMENT OF SOCIAL
AND REHABILITATION SERVICES

JANET SCHALANSKY, ACTING SECRETARY

February 13, 1995

The Honorable Jo Ann Pottorff, Chair
House Select Committee on Developmental
Disabilities
Statehouse
300 SW 10th Ave., Room 183-W
Topeka, KS 66612-1504

Dear Representative Pottorff:

Staff in Mental Health and Retardation Services have informed me your Select Committee on Developmental Disabilities has a question on how the numbers of families selected to receive family subsidy are arrived at for each county.

All applicants for family subsidy were grouped according to Community Mental Retardation Center (CMRC) catchment area. The population total of the counties comprising the CMRC catchment area were pooled and then prorated according to statewide population in order to arrive at a per cent of population for the catchment area. The per cent arrived at was applied to the applicant list for family subsidy using a computerized random drawing.

I hope this answers adequately the question that arose. If you desire additional explanation, feel free to contact me at 296-3274 or Commissioner Vega at 296-3773.

Sincerely,

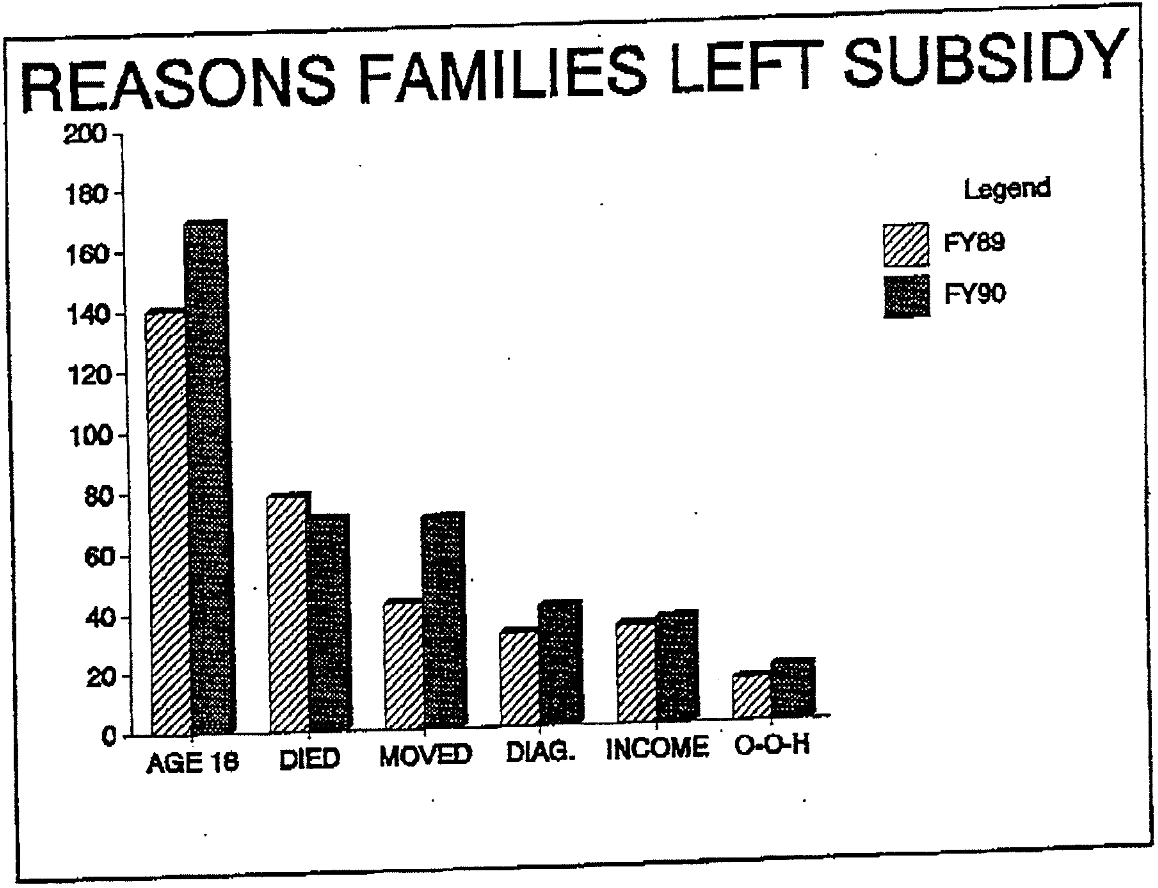
Janet Schalansky

Janet Schalansky
Acting Secretary

JS:GDV:DH:eb

915 SW HARRISON STREET, TOPEKA, KANSAS 66612

2-18



A Total of 741 Families Left the Subsidy Program During FY89 and FY90; 309 Because the Child Became an Adult at 18 Years Old

The reasons the 741 families left the Subsidy during FY89 and FY90: (Fig. 9)

FY89	FY90	
140	169	Children turned 18
78	71	Children died
42	70	Families moved out of Michigan
31	40	Children had a change in diagnostic category which made them ineligible for the Subsidy
33	35	Families' incomes went above the allowed amount
14	18	Children were placed out-of-home
338	403	TOTAL

PERFORMANCE AUDIT REPORT

REVIEWING THE TRANSFER OF MENTALLY RETARDED PATIENTS FROM STATE INSTITUTIONS TO COMMUNITY LIVING FACILITIES

APRIL 1994

OBTAINING AUDIT INFORMATION

This audit was conducted by Ellyn Sipp, Nancy Case, and Cindy Denton. If you need any additional information about the audit's findings, please contact Ms. Sipp at the Division's office.

94-36

House Select Committee on
Developmental Disabilities
2-8-95
Attachment 3

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SUMMARY OF AUDIT FINDINGS

REVIEWING THE TRANSFER OF MENTALLY RETARDED PATIENTS FROM STATE INSTITUTIONS TO COMMUNITY LIVING FACILITIES

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REVIEWING THE TRANSFER OF MENTALLY RETARDED PATIENTS FROM STATE INSTITUTIONS TO COMMUNITY LIVING FACILITIES

Summary of Legislative Post Audit's Findings

How many patients have transferred from State mental retardation hospitals to community facilities in recent years? In 1991, the State established goals to reduce hospital populations by more than 280 individuals by the end of fiscal year 1994. Since that time, hospital populations have been reduced by 186 residents. A total of 107 residents have been transferred as a result of a formal placement process specifically designed to meet hospitals' population-reduction goals. Even with all these transfers, hospital populations remain higher than planned. To meet their goals, State hospitals will have to transfer enough residents to community settings to reduce populations by another 98 individuals during the last half of fiscal year 1994. This rate of transfer would be at least three times the rate that hospitals have been transferring residents to community settings.

What factors are keeping more patients from transferring from State mental retardation hospitals to community facilities? One factor is that families are not always interested in placing their family members in the community. Also, the placement approach adopted by the State depends on developing individualized services which may not be readily available. Most of the time spent getting hospital residents transferred is spent waiting while community facilities develop individual placements. Community facilities cite staff and financial resource inadequacies as the main reason why these placements are not being developed as quickly as anticipated. Other factors that tend to slow down the placement process include the lack of early community facility involvement in the process, a lack of referrals to community facilities, and a lack of follow-up on referrals. The Department of Social and Rehabilitation Services said it was taking steps to address these latter issues.

The original population-reduction goals may have been optimistic. Finally, per-person costs for community placements average about $50,000 a year, while per-person hospital costs average about $85,000 a year. However, even though people are being transferred from hospitals to community settings, total State hospital costs are not going down. In fact, the State will not realize any significant cost savings from transferring individuals to community settings until a hospital is closed.

This report includes several recommendations for improving the placement process. Recommendations also are made to review the population-reduction goals and to consider whether the State should move more quickly to close a mental retardation hospitals. We would be happy to discuss these recommendations or any other items in the report with any legislative committees, individual legislators, or State officials.

Barbara J. Hinton

Barbara J. Hinton
Legislative Post Auditor

Reviewing the Transfer of Mentally Retarded Patients From State Institutions to Community Living Facilities

Over the past several years, the Governor has proposed and the Legislature has approved reduced staffing levels at the State mental health and retardation hospitals, with the understanding that patients would be transferred from these State institutions to community living facilities.

During the 1993 biennial legislative bus tour of State agencies and programs, however, legislators were informed that patient populations at the mental retardation hospitals essentially had not dropped. By the middle of this fiscal year, some 27 mentally retarded hospital residents had been transferred from Kansas Neurological Institute and Parsons and Winfield State Hospitals, but 98 additional residents must be transferred before the fiscal year's end to meet budgeted hospital population levels. Hospital and Department of Social and Rehabilitation Services officials generally indicated that community services were not readily available. However, officials at a number of community living facilities visited during the tour indicated that services were available, or could be, if patients were referred to them.

Staffing levels at the hospitals have been reduced in anticipation of the reduced hospital populations. If populations are not reduced as expected, staffing levels may have to be increased, which could have a major financial impact on the State.

To address concerns about what factors are keeping patients from being transferred from State institutions to community facilities, and why, this audit answers the following questions:

1. **How many patients have transferred from State mental retardation hospitals to community facilities in recent years?**
2. **What factors are keeping more patients from transferring from State mental retardation hospitals to community facilities?**

To answer these questions, we reviewed State mental retardation hospital records and interviewed hospital officials. We also interviewed officials from the Department of Social and Rehabilitation Services, a sample of community facilities, and other appropriate agencies. In addition, we visited two community facilities, and interviewed a sample of parents of hospital residents who had been transferred to the community. In conducting this audit, we followed all applicable government auditing standards set forth by the U.S. General Accounting Office.

In general, we found that the State has made a policy decision to move mentally retarded individuals from institutional to community settings. As a result, the proportion of State dollars going to community services has been increasing. The State has established goals to reduce hospital resident populations and staffing levels.

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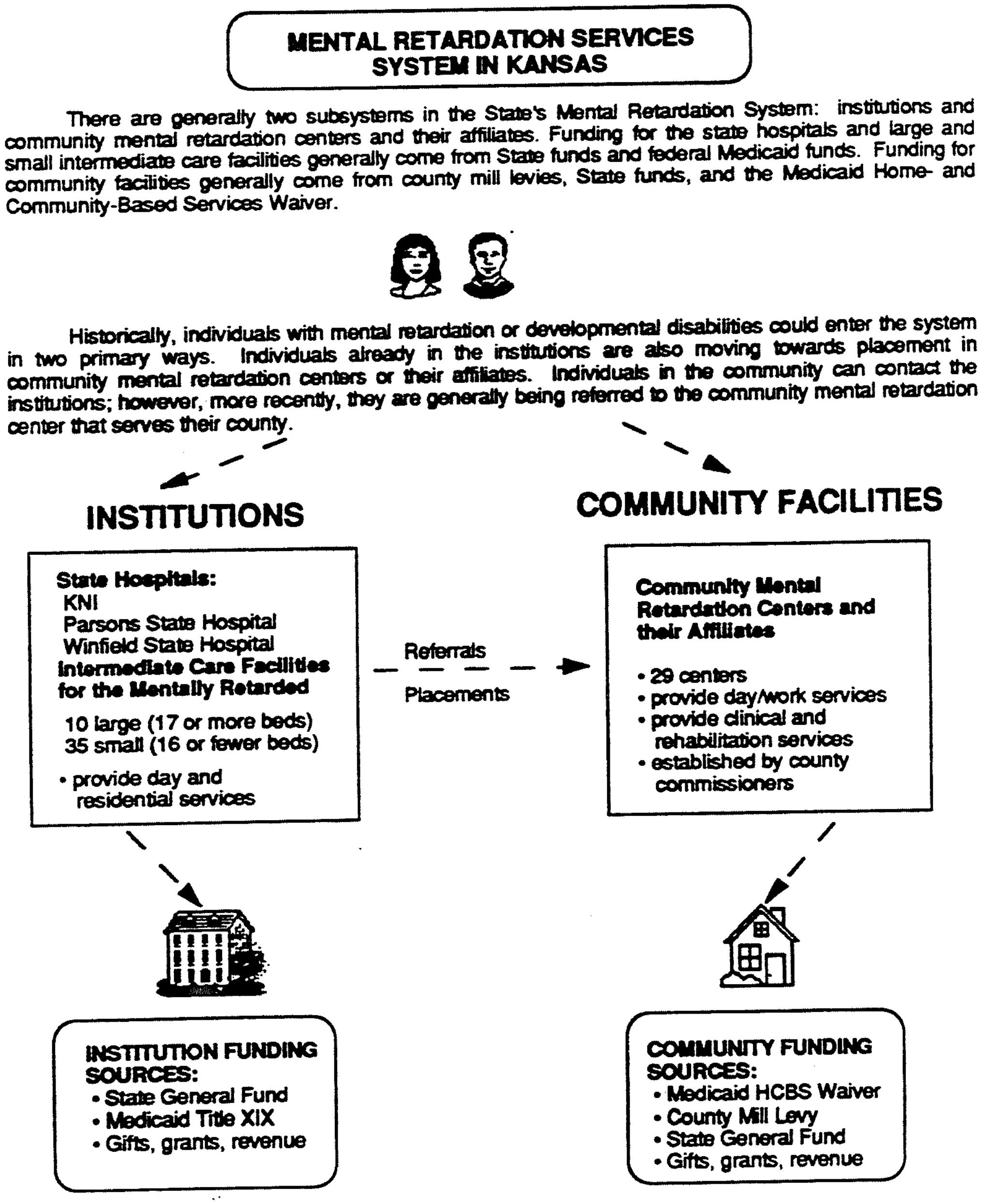
Although the State has limited admissions and transferred more than 250 hospital residents to community settings since fiscal year 1991, hospital populations remain higher than planned. One reason is that the State's placement approach depends on developing individualized community services and placements, many of which are not readily available.

Community centers primarily cite resource inadequacies as the reason why services and placements are not being developed rapidly. We also found that the original population-reduction goals may have been overly optimistic. Finally, per-person costs for community placements appear to be less than per-person hospital costs. However, even though people are being transferred from hospitals to community settings, total State hospital costs are not going down. In fact, the State will not realize any significant cost savings from transferring individuals to community settings until a hospital is closed.

These and related findings will be discussed in more detail after a brief overview.

Overview of the System for Meeting the Needs of Mentally Retarded and Developmentally Disabled Kansans

Kansas provides services to mentally retarded and developmentally disabled Kansans in both institutional and community settings. These individuals include persons with IQs of 70 or below who require special protection and services, and persons who have other developmental disabilities including epilepsy, cerebral palsy, or autism. Throughout this report, we use the term mentally retarded to describe persons with all types of developmental disabilities. The following graphic illustrates the main features of the State's system for meeting the needs of mentally retarded Kansans.



MENTAL RETARDATION SERVICES SYSTEM IN KANSAS

There are generally two subsystems in the State's Mental Retardation System: institutions and community mental retardation centers and their affiliates. Funding for the state hospitals and large and small intermediate care facilities generally come from State funds and federal Medicaid funds. Funding for community facilities generally come from county mill levies, State funds, and the Medicaid Home- and Community-Based Services Waiver.

Historically, individuals with mental retardation or developmental disabilities could enter the system in two primary ways. Individuals already in the institutions are also moving towards placement in community mental retardation centers or their affiliates. Individuals in the community can contact the institutions; however, more recently, they are generally being referred to the community mental retardation center that serves their county.

INSTITUTIONS

State Hospitals:
KNI
Parsons State Hospital
Winfield State Hospital
Intermediate Care Facilities for the Mentally Retarded
10 large (17 or more beds)
35 small (16 or fewer beds)
- provide day and residential services

Referrals

Placements

COMMUNITY FACILITIES

Community Mental Retardation Centers and their Affiliates
- 29 centers
- provide day/work services
- provide clinical and rehabilitation services
- established by county commissioners

INSTITUTION FUNDING SOURCES:
- State General Fund
- Medicaid Title XIX
- Gifts, grants, revenue

COMMUNITY FUNDING SOURCES:
- Medicaid HCBS Waiver
- County Mill Levy
- State General Fund
- Gifts, grants, revenue

As the graphic shows, the institutional settings include three State mental retardation hospitals: Parsons State Hospital, Kansas Neurological Institute in Topeka, and Winfield State Hospital. These hospitals provide residential services to approximately 850 mentally retarded and developmentally disabled Kansans. In addition, the hospitals offer individualized treatment programs for each resident in such areas as communication skills development, special education, and vocational training. The hospitals are funded primarily by a combination of State and federal funds.

The other type of institutional setting is intermediate care facilities for the mentally retarded. The State licenses 10 large (17 or more beds) and 35 small (16 or fewer beds) intermediate care facilities for the mentally retarded that provide active treatment programs for mentally retarded individuals. These facilities, which are funded primarily with Medicaid dollars, contain a total of 961 beds, two-thirds of which are in the large facilities.

As part of the State's deinstitutionalization effort, the Department of Social and Rehabilitation Services is in the process of phasing-out the large intermediate care facilities for the mentally retarded, and is not licensing any new beds in small facilities. Department officials also told us that a number of small intermediate care facilities for the mentally retarded have been converted to less restrictive settings, such as group homes.

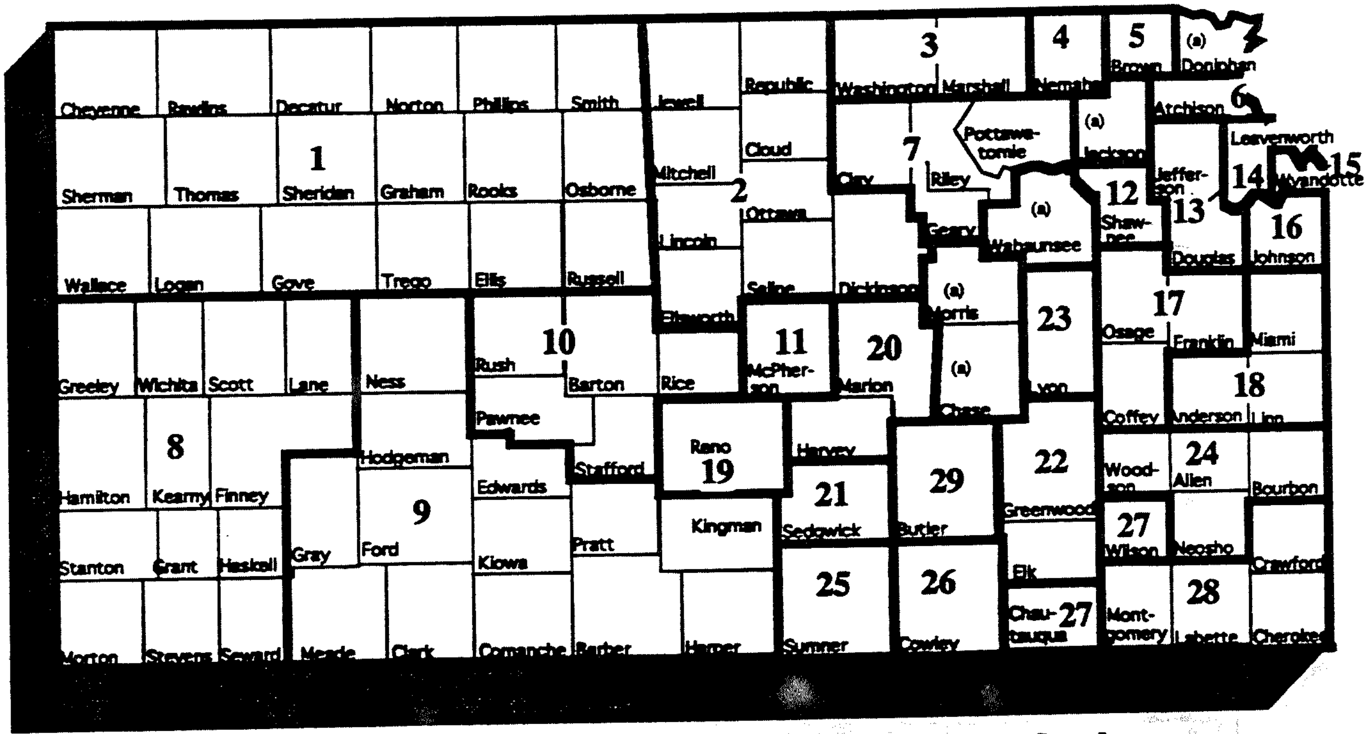
The graphic also shows that community services are provided by 29 community mental retardation centers that have been established across the State. State law authorizes county commissioners of one or more counties to establish these centers to serve mentally retarded individuals in their counties. The map on the next page shows where these centers are located.

Community mental retardation centers are authorized to provide a variety of services, including preschool, day care, work activity, sheltered workshops, sheltered living, clinical services, and rehabilitation services. They also operate a majority of the State's small intermediate care facilities for the mentally retarded. The centers can provide services directly or through contracts with affiliated agencies or individuals. The centers, which serve about 4,200 individuals, receive both State and federal funds. They also receive money from their counties, which can levy up to two mills for services to the mentally retarded.

The State Has Made a Policy Decision to Move Mentally Retarded Individuals From Institutional to Community Settings

Over the last several years, the State has been reducing its reliance on State hospitals and intermediate care facilities for mentally retarded citizens, and moving towards increased use of community facilities. The reasons for this shift appear to be two-fold: community settings are thought to be more appropriate than institutional settings, and they are perceived to be more cost-effective.

Community Mental Retardation Centers in Kansas



1=Developmental Services of Northwest Kansas, Hays
2=Occupational Center of Central Kansas, Inc., Salina
3=Twin Valley Developmental Services, Greenleaf
4=Nemaha County Training Center, Seneca
5=Brown County Developmental Services, Inc., Hiawatha
6=Achievement Services for Northeast Kansas, Atchison
7=Big Lakes Developmental Center, Inc., Manhattan
8=Southwest Developmental Services, Inc., Garden City
9=Arrowhead West, Inc., Dodge City
10=Sunflower Training Center, Inc., Great Bend
11=McPherson County Diversified Services, Inc., McPherson
12=Topeka Association for Retarded Citizens, Inc., Topeka
13=Cottonwood, Inc., Lawrence
14=Handicapped Education & Living Programs, Inc., Leavenworth
15=Wyandotte Developmental Disabilities Services, Kansas City
16=Johnson County Mental Retardation Center Lenexa
17=COF Training Services, Inc., Ottawa
18=Tri-Ko., Inc., Osawatomie
19=Training & Evaluation Center for the Handicapped, Inc., Hutchinson
20=Northview Developmental Services, Inc., Newton
21=Sedgwick County Mental Retardation Governing Board, Wichita
22=Terramara, Inc., El Dorado
23=Hetlinger Developmental Center & Sheltered Workshop, Inc., Emporia
24=Tri-Valley Developmental Center, Inc., Chanute
25=Futures Unlimited, Inc., Wellington
26=Cowley County Developmental Services, Inc., Arkansas City
27=New Beginnings Enterprises, Independence
28=CLASS, Limited, Columbus
29=Flinthills Services, Inc., El Dorado

(a)=not currently served

The Legislature has closed one State hospital and has struggled with the issue of closing another. In October 1988, the State closed Norton State Hospital, one of four State mental retardation hospitals. During the 1990 legislative session, the House Appropriations Subcommittee considering the hospitals' budgets recommended closing one of the remaining three mental retardation hospitals. The corresponding Senate Ways and Means Subcommittee did not agree with this recommendation. A compromise required the Department of Social and Rehabilitation Services to develop and implement a plan by the 1991 legislative session that would move 50 residents from the State hospitals to community settings.

The Department prepared a plan that would reduce hospital populations from 965 residents at the end of fiscal year 1991 to 743 residents by the end of fiscal year 1994. It also developed a new approach to transferring hospital residents to community settings. In anticipation of these population reductions, the Department planned staffing reductions at each of the State's mental retardation hospitals.

In its interim report to the 1992 Legislature, the Task Force on Social and Rehabilitation Services (a group of 17 legislators and seven members of the public) again recommended that one of the State's mental retardation hospitals be closed. In conjunction with that recommendation, the Task Force adopted a five-year plan developed by the Department of Social and Rehabilitation Services that would further reduce hospital populations to 497 by the end of fiscal year 1997. The Task Force also made recommendations to strengthen the community services system by such actions as establishing a State-level presence in area Department of Social and Rehabilitation offices to monitor service provision, quality, and planning; establishing quality enhancement processes; establishing salary enhancements for community facility staff; and establishing reimbursement levels that are based on individuals' needs.

As a result of Committee deliberations, the 1992 Legislature inserted a proviso in the State hospitals' appropriations bill that made any closing of a mental retardation hospital subject to the approval of the 1993 Legislature. In 1993, the House wrestled with the issue of closing one of the State mental retardation hospitals. The Department of Social and Rehabilitation Services recommended closing Winfield State Hospital, but, after a series of hearings, the House Appropriations Committee recommended closing Kansas Neurological Institute. That recommendation was not debated by the full House, and was never taken up by the Senate.

Although no decision was made on closing a State hospital, the Legislature did take a number of actions designed to increase the rate of transfer of residents from State hospitals to community settings. These actions included making start-up funds available to community agencies to help defray some of the costs of serving hospital residents.

One National Trend Is to Close State Mental Retardation Hospitals

We reviewed what is taking place in other states in the area of providing services to mentally retarded citizens and found that nearly all states are moving in the direction of closing or downsizing their public mental retardation hospitals. According to a study conducted by the National Association of State Directors of Developmental Disabilities Services, the reasons for these trends are: the shift to community-based care, responses to federal hospital certification surveys, and the rising costs of services in such facilities.

Nationwide, the number of State-owned mental retardation hospitals has declined from 278 at the end of fiscal year 1988 to 236 at the end of fiscal year 1993. The number is expected to drop further to 215 by the end of 1995.

According to an official with the National Association of State Directors of Developmental Disabilities Services, New Hampshire and Vermont no longer have any State-owned mental retardation hospitals. This official also said that Rhode Island and Michigan would be closing all their hospitals in the next year or so, and that New York would be closing its remaining 10 hospitals by the year 2000 (it already has closed 10).

Hospital populations also are declining. Between fiscal year 1988 and 1993, nationwide hospital populations declined from about 92,000 to 71,000 residents. Over that same time period, average hospital populations fell from 329 to 299 persons. It is anticipated that the number of persons served in state mental retardation hospitals will continue to decline.

As a Result of Policy Decisions, the Proportion of State Funds Spent for Institutional Services For the Mentally Retarded Is Declining, While the Proportion Spent for Community Services Is Increasing

Historically, the State has devoted the bulk of its resources to institutional services for the mentally retarded. A major reason: Medicaid funds from the federal government were available primarily for institutional services. In the early 1980s, the federal government allowed states to use Medicaid money for home- and community-based services through a waiver of the Medicaid rules. States may obtain this waiver if they can demonstrate that community services are more cost-effective than institutional services. The overall objective of the waiver is to reduce institutional populations. In fiscal year 1992, Kansas was authorized a waiver that gave it the flexibility to use federal Medicaid money, which previously was restricted to use in institutional settings, to pay for home- and community-based services for the mentally retarded.

State expenditures for institutional services for mentally retarded individuals have remained relatively constant over the past five years. As the State has moved towards greater emphasis on community services, it has limited the growth of new institutional services. As noted earlier, the State is phasing out large intermediate care facilities for the mentally retarded, and is not licensing any new small facilities. The table below and on the following page shows the amount of State expenditures for institutional services since fiscal year 1990.

State Expenditures for Institutional Services For the Mentally Retarded (in millions)

	Fiscal Year					
	1990	1991	1992	1993	1994 (est.)	% Change 1990-1994
State Hospitals						
State General Fund includes the State match for Medicaid (59% federal, 41% State)	$32.8	$31.0	$32.5	$31.3	$27.7	(15.6)%
Medicaid (federal) these revenues come from daily rates paid to hospitals for residents eligible for Medicaid	35.2	38.5	37.3	37.7	39.7	13.0
Other Funds includes hospital resident fees, and funds for capital improvements and foster grandparents	4.0	5.8	5.7	4.6	3.9	(2.5)
Sub Total, State Hospitals	$72.0	$75.3	$75.5	$73.6	$71.3	(.8)%
ICFMR (Medicaid) this includes the State and federal expenditures for these facilities (59% federal, 41% State)	26.3	30.6	33.4	35.9	35.3	34.1
Total, All Institutions	$98.3	$105.9	$108.9	$109.5	$106.6	8.5%

As the table shows, State expenditures for institutional services have remained relatively constant over the past five years. What growth there has been occurred in the intermediate care facilities for the mentally retarded. However, the chart on the following page shows that, as a proportion of total expenditures for mental retardation services, institutional expenditures have declined from 79.4 percent to 62.1 percent.

Interestingly, even though some hospital residents are transferring to community settings, there has not been a corresponding drop in Medicaid expenditures at the State hospitals because Medicaid reimbursements are based on the hospital's costs. Because those costs have not changed much, Medicaid expenditures also have not changed much. In essence, what has happened is that the daily rate per resident has climbed because the hospitals' costs are allocated over a smaller number of residents.

State expenditures for community services to mentally retarded individuals have grown significantly since 1990. As the following table shows, these expenditures have grown from $25.5 million in fiscal year 1990 to an estimated $65.1 million in fiscal year 1994, an increase of nearly 156 percent.

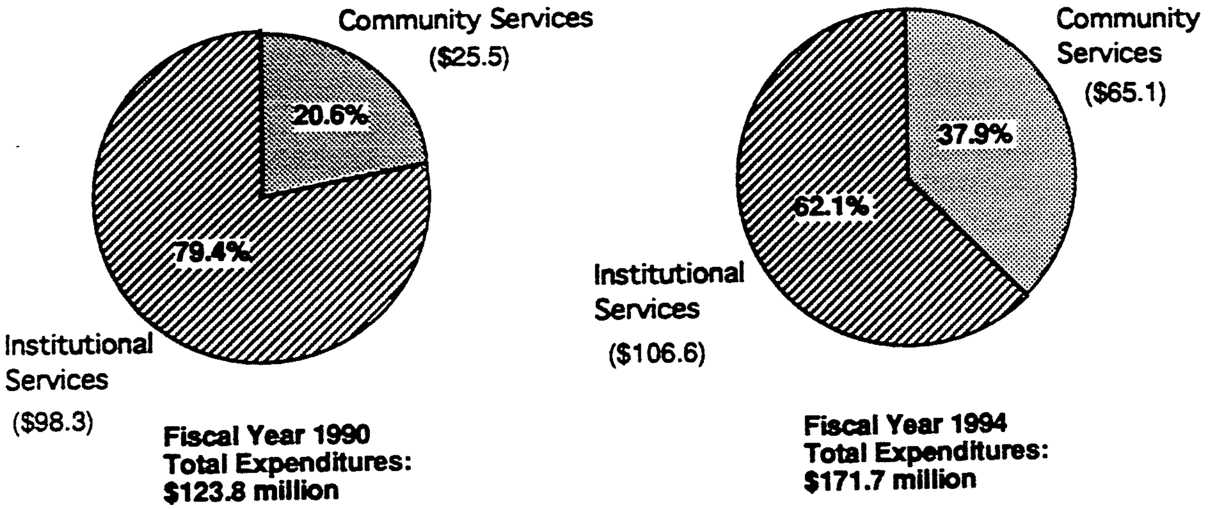
State Expenditures for Community Facility Services (a)
(In millions)

	Fiscal Year				(est.)	% Change
	1990	1991	1992	1993	1994	1990-1994 (b)
Special Purpose Grants these are awarded to community facilities to provide specific services	$7.5	$11.5	$13.7	$15.5	$12.1	62.9%
Social Service Block Grant this money comes from the federal government on a formula basis to fund services to a specific number of people	9.9	10.3	10.3	10.3	10.4	5.1
State Aid this money is distributed to community mental retardation facilities on the basis of population	6.1	6.0	6.0	6.0	6.0	(1.8)
Medicaid this money is used to provide community services, and includes both State and federal moneys (59% federal, 41% State)	2.0	6.8	8.7	18.6	34.1	1,613.5
Family Subsidy/Support these grants are provided to families to help them pay for extraordinary expenses incurred in caring for their mentally retarded children	0.0	0.0	.4	1.5	2.5	525.0
Totals	$ 25.5	$34.6	$39.1	$51.9	$65.1	155.7%

(a) In addition to these expenditures, the State also pays for medical expenses for mentally retarded Kansans who are eligible for Medicaid.

(b) The Family Subsidy/Support percentage change is from fiscal years 1992 to 1994.

State Expenditures for Institutional and Community Services for Mentally Retarded Persons



These charts show that community services represent an increasing proportion of all Sate expenditures for services to mentally retarded individuals. They've grown from 20.6% of all expenditures in fiscal year 1990 to nearly 38% in fiscal year 1994.

The table shows that Medicaid moneys for services provided by community facilities, which have become available under the waiver program, have grown dramatically. As a result, the proportion of total expenditures for mental retardation services going to community facilities has grown from 20.6 percent to 37.9 percent.

How Many Patients Have Transferred from State Mental Retardation Hospitals to Community Facilities In Recent Years?

In 1991, the State established goals to reduce hospital populations by more than 280 individuals by the end of fiscal year 1994. Since that time, hospital populations have been reduced by 186 residents. A total of 107 residents have been transferred as a result of a formal placement process specifically designed to meet hospitals' population-reduction goals. Even with all these transfers, hospital populations remain higher than planned. To meet their goals, State hospitals will have to transfer enough residents to community settings to reduce populations by another 98 individuals during the last half of fiscal year 1994.

The State Has Established Goals To Reduce Hospital Resident Populations and Staffing Levels

In 1991, the Department of Social and Rehabilitation Services, working with the Legislature, established population-reduction goals for each of the three State mental retardation hospitals. Because reduced populations would require fewer staff, the Department also planned to reduce staffing levels at the hospitals. The Governor and Legislature essentially used the Department's figures in the budget and appropriations process. The following table shows the population goals and staffing limits established.

State Hospital Resident Population Targets and Staffing Limits Fiscal Year

	Actual	Goals				Reduction	
	1990	1991	1992	1993	1994	No.	%
Population Goals (Year End)	1,027 (a)	965	912	828	743	284	23.0%
Staffing Levels (Authorized)	2,409	2,445	2,418	2,286	2,191	218	9.0%

(a) This figure represents the actual year-end population for fiscal year 1990. It is the base from which hospital populations were reduced.

The table shows that populations were to be reduced by 284 individuals by the end of fiscal year 1994. (The full, five-year plan adopted by the 1991 interim Task Force on Social and Rehabilitation Services calls for hospital resident population to be reduced to 497 by the end of fiscal year 1997, at which time one of the mental retardation hospitals would be closed.) The table also shows that the number of full-time-equivalent employees was to be reduced by nine percent by fiscal year 1994.

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To Meet the Hospital Resident Population Goals, The State Hospitals Have Limited Admissions and Transferred Residents to Community Settings

Since 1991, individuals have moved into and out of State hospitals for a variety of reasons. As the accompanying table shows, far more people have left the hospitals than have come into the hospitals in recent years. (Appendix A presents this information for each mental retardation hospital.)

State Hospital Resident Population Changes
Fiscal Year

	1991	1992	1993	1994 (a)	Totals
People have entered State hospitals for the following reasons...					
they were admitted for the first time	26	31	3	1	61
they were readmitted after being discharged	9	8	4	6	27
they were returned from a community placement that didn't work out	12	17	10	2	41
Total Movement Into the Hospital	**47**	**56**	**17**	**9**	**129**
People have left State hospitals for the following reasons...					
they were discharged when they no longer needed hospital services	4	4	5	5	-18
they died	14	17	10	5	-46
they were transferred to community settings as part of a formal placement process designed to reduce hospital populations (b)	na	43	39	25	-107
they were placed in family-living settings like therapeutic foster care, or in community settings, but <u>not</u> as part of the formal placement process	79	47	16	4	-146
Total Movement Out of the Hospital	**-97**	**-111**	**-70**	**-39**	**-317**
Change in Resident Population Not Explained by Above (c)	**+4**	**-3**	**+4**	**-3**	**+2**
Change in Resident Population from Previous Year	**-46**	**-58**	**-49**	**-33**	**-186**

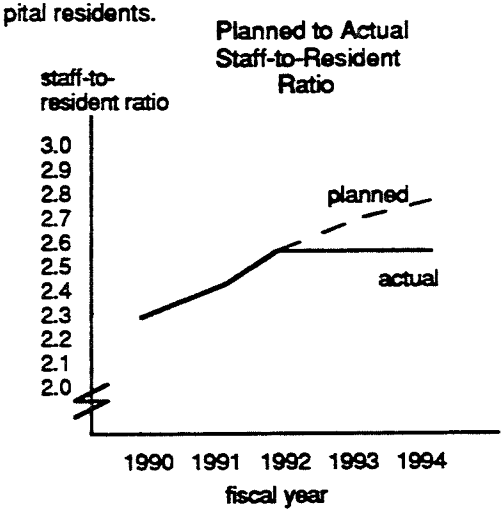
(a) Data from two hospitals were through December 1993; data for the third were through February 1994.
(b) These project placements represent those identified by the hospitals.
(c) These unexplained changes result from inconsistencies in the way the hospital data were reported to us by the hospitals.

A Comparison of Planned-to-Actual Hospital Staff-to-Resident Ratios Shows That the Hospitals Should Not Have Any Imminent Problems With Federal Certification

When the hospital population-reduction goals were established, the Department of Social and Rehabilitation Services reduced authorized staffing levels at all three hospitals to reflect these reduced populations. In 1990, there were 2.3 staff per resident in hospitals. Given that there was to be a proportionately bigger reduction in hospital residents than in staff, by 1994, hospitals expected to have nearly 3 staff members for every resident.

This report notes that resident populations have not been reduced as fast as anticipated. At the same time, authorized staffing levels have been reduced as originally planned. Because of this, concerns have been raised that the hospitals could face certification problems related to insufficient staff levels. If this occurs, the State could be in danger of losing federal Medicaid dollars.

The following chart compares the planned-to-actual ratios of staff members to hospital residents.



As of the end of December 1993, hospitals had 2.6 staff members for every resident. The chart shows that the actual number of staff members per resident is fewer than expected. However, it is more than the hospitals had in 1990, and the ratio has remained steady since 1992.

We talked with officials from the hospitals and from the Department of Health and Environment, which is responsible for conducting the certification surveys for the federal government. All indicated that none of the hospitals were in danger of losing their certification, even with the decrease in staff levels.

State hospitals have severely limited admissions in recent years. As the table shows, hospitals' admissions were cut dramatically in fiscal year 1993 and 1994. Hospitals officials we talked with said they were admitting new residents only in cases of emergency, or upon request of the Department of Social and Rehabilitation Services.

We also looked to see whether the action of limiting admissions meant that hospital waiting lists were growing. We found that this wasn't the case. Hospital officials told us that when individuals inquire about entering the hospitals, they are referred for community services and not put on a waiting list. In fact, Winfield State Hospital officials said they had no one on a waiting list. Kansas Neurological Institute has three individuals on a waiting list, but they have been on that list since 1990.

Parsons State Hospital was the only institution that had a significant number of individuals on a waiting list. It had 26 people waiting for hospital services. The most recent addition to the list was made in September 1992.

Of the 253 individuals who transferred to community settings since fiscal year 1991, 107 moved as a result of the placement project initiated to reduce hospital populations. In an effort to meet the population-reduction goals established by the Department of Social and Rehabilitation Services, the hospitals embarked on a formal project in mid-1991 to transfer clients to the communities. This project is described more fully in question two of this report. One reason this effort was initiated was to ensure that individuals who were transferred did not return to the hospital. As the table shows, these "placement returns" had been as high as 17 individuals in fiscal year 1992.

Two hospitals, Kansas Neurological Institute and Winfield State Hospital, participated in the placement project during fiscal year 1992. Parsons State Hospital joined them in fiscal year 1993. As the table shows, since 1993, this project has been the major vehicle by which individuals have been permanently transferred from State hospitals to community settings.

Even With All These Transfers, Hospital Populations Remain Higher Than Planned

The following table compares the hospital resident population goals with actual year-end populations.

State Mental Retardation Hospital
Population Targets

Fiscal Year-End

	1991	1992	1993	1994
Population Goals	965	912	828	743
Actual Population	981	923	874	841 (a)
Difference	-16	-11	-46	-98

(a) This figure is actual population as of December 31, 1993.

As the table shows, population goals have not been met. Further, to meet the 1994 fiscal year-end goal of 743, hospital populations will have to be reduced by a total of 98 more people. Appendix B presents this information for each mental retardation hospital.

What Factors Are Keeping More Patients From Transferring from State Mental Retardation Hospitals to Community Facilities?

Previous sections of this report showed that the transfer of hospital clients to community settings was slower than anticipated. We identified several reasons for this. Families are not always interested in placing their family members in community settings. Also, the placement approach adopted by the State depends on developing individualized services which may not be readily available. Most of the time spent getting hospital residents transferred is spent waiting while community facilities develop individual placements. Community facilities cite staff and financial resource inadequacies as the main reasons why these placements are not being developed as quickly as anticipated.

We also identified other factors that tend to slow down the placement process, including the lack of early community facility involvement in the process, the lack of referrals to community facilities, and the lack of follow-up on referrals. Department of Social and Rehabilitation Services officials indicated they were taking steps to address many of these issues. We also found the original population-reduction goals may have been optimistic. Finally, per-person costs for community placements appear to be less than per-person hospital costs. However, even though people are being transferred from hospitals to community settings, total State hospital costs are not going down. In fact, the State will not realize any significant cost savings from transferring individuals to community settings until a hospital is closed.

Families Are Not Always Interested in Placing Their Family Members in Community Settings

Families have the unilateral decision-making power in the placement process. Hospital staff talk to families regularly to see if they are interested in placing their family members in the community, but families make the final decisions as to whether they want their family members to be placed in the community.

Clearly, not all families have made that choice: only 238 hospital residents have been involved in the placement project to-date, although other residents may have been placed on waiting lists for community services. Families of the other hospital residents have not agreed to community placements, and one hospital said that obtaining parental consent for placement sometimes can be difficult.

Community facility officials told us that families sometimes fear the community facility will not be in business forever, and that they are concerned for the future. One official said problems have occurred when companies that hired mentally retarded individuals went out of business. The mentally retarded individuals could not go immediately back to a sheltered workshop because there were no openings. As a result, they had to be placed on a waiting list again. Another community official said that families did not want to place their family members in a large urban area.

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Department of Social and Rehabilitation Services officials said they are trying to promote the idea of community placements among parents who indicate they are not interested in such placements for their family members. The Department is encouraging such actions as regional meetings for parents and community providers. The Department also is encouraging ongoing contacts with parents by hospital social workers and superintendents, and through regular newsletters.

Even when they have decided to try for a community placement, hospital residents' families can decide whether they want to accept a particular community-setting option. In 13 of the 238 cases we reviewed, we found that families rejected community placements because they did not like the facilities that would provide the services to their family members. This rejection slowed the transfer process down considerably, because the hospitals had to locate new facilities that would accept the family members.

The Department's and State Hospitals' Placement Approach Depends on Developing Individualized Community Services And Placements, Many of Which Are Not Readily Available

In the past, hospital residents were transferred to community settings following the "developmental" model of placement. Under this approach, individuals would be transferred to existing openings in community facilities. Frequently, the initial transfer would be to an intermediate care facility for the mentally retarded. The community facility would provide services to the transferred individuals so that they could develop their skills and abilities. As they progressed to higher levels of development, they would earn the right to transfer to increasingly less restrictive settings, such as group homes. This approach was tied to the already existing types of specialized living and work environments. Generally, the approach revolved around fitting mentally retarded individuals into available openings, or finding the "right" individual to fill a particular slot.

The State's new placement approach allows hospital residents and their families to specify what services and activities the residents will need in the communities. The placement approach State hospitals initiated in their attempt to meet the reductions in hospital resident populations was carried out through the "community integration project." The purpose of the project was to permanently place hospitals residents in community settings. The chart on the following page shows how the new approach used in this project works.

This new approach is "person-centered," which assumes that mentally retarded individuals or their families best know their own needs, and should be allowed to direct their own lives as much as possible. Rather than residents earning the right to move to less-restrictive settings, this approach assumes that mentally retarded individuals can live in any type of setting they desire, so long as proper supports are provided. The key is that this approach focuses on the individual and his or her needs

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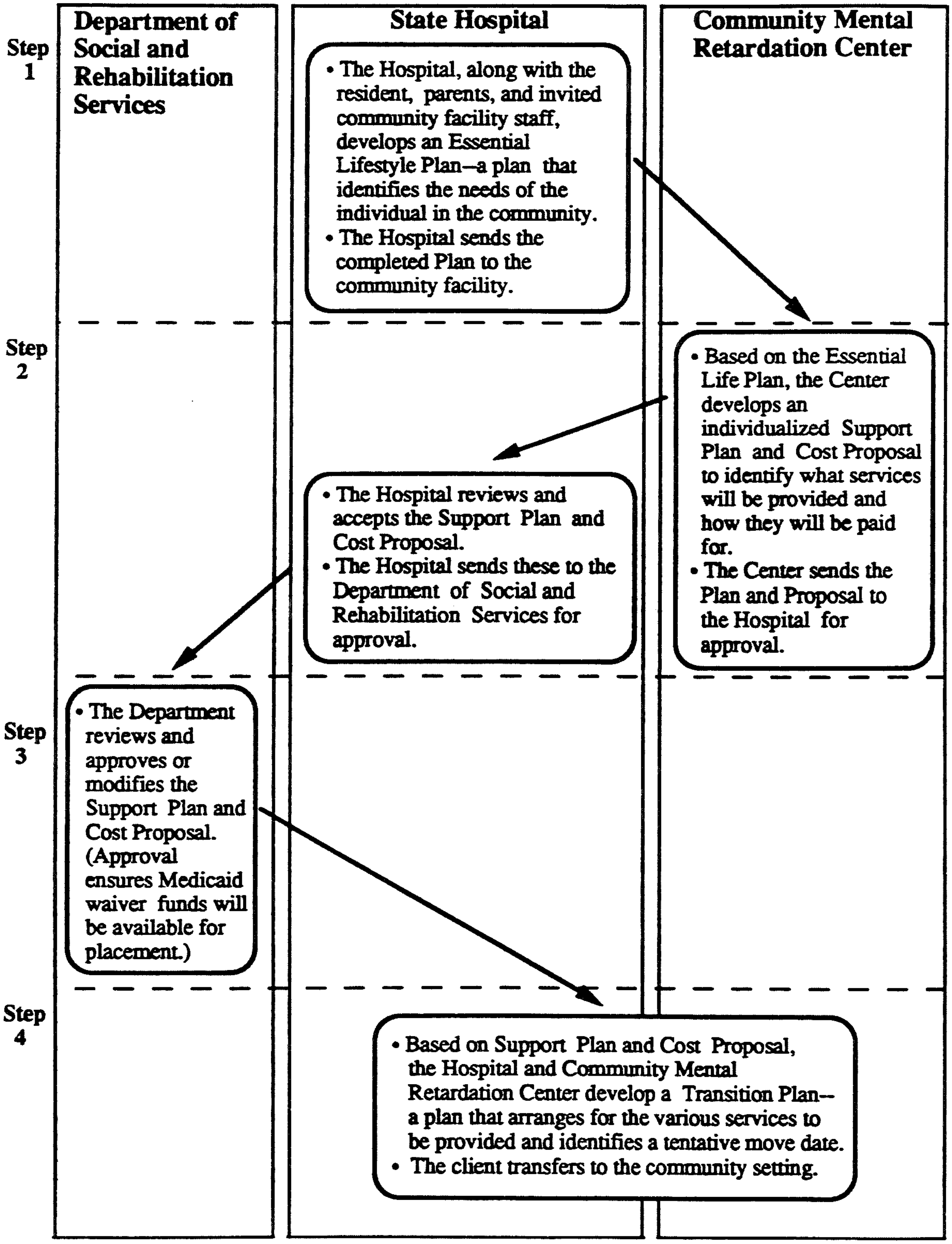
Community Integration Project Placement Process



Step 1 — State Hospital

- The Hospital, along with the resident, parents, and invited community facility staff, develops an Essential Lifestyle Plan–a plan that identifies the needs of the individual in the community.
- The Hospital sends the completed Plan to the community facility.

Step 2 — Community Mental Retardation Center

- Based on the Essential Life Plan, the Center develops an individualized Support Plan and Cost Proposal to identify what services will be provided and how they will be paid for.
- The Center sends the Plan and Proposal to the Hospital for approval.

Step 2 — State Hospital

- The Hospital reviews and accepts the Support Plan and Cost Proposal.
- The Hospital sends these to the Department of Social and Rehabilitation Services for approval.

Step 3 — Department of Social and Rehabilitation Services

- The Department reviews and approves or modifies the Support Plan and Cost Proposal. (Approval ensures Medicaid waiver funds will be available for placement.)

Step 4 — State Hospital and Community Mental Retardation Center

- Based on Support Plan and Cost Proposal, the Hospital and Community Mental Retardation Center develop a Transition Plan–a plan that arranges for the various services to be provided and identifies a tentative move date.
- The client transfers to the community setting.

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and desired lifestyle, rather than on fitting individuals to existing openings. As a result, individualized community placements are developed for each hospital resident who is participating in the placement project.

The State reimburses the community facilities on the basis of individualized rates for each hospital resident transferred. (Before this project, community facilities received a set per-diem rate for transferred hospital residents based on their levels of disability and the types of services they received. That is still the reimbursement method used for placements of individuals who already are in the community.)

Theoretically, the individualized nature of the placements should lead to higher-quality placements. These higher-quality placements should, in turn, reduce the number of transferred individuals who return to the hospital setting. (According to hospital staff, this appears to be happening. Only three of 107 individuals who have been placed as part of the placement project have been returned to a hospital.) The overall result should be a higher number of <u>permanent</u> placements in community settings.

In conjunction with this new approach, the Department is phasing out intermediate care facilities for the mentally retarded by not transferring any hospital residents to such facilities. The Department also is not entering into contracts with new facilities. In addition, the Department is not entering into contracts for new group homes or for expansions of existing group homes.

People involved with this new placement approach all said it was superior to previous placement approaches. The profile to the right summarizes some of their comments.

Most of the time spent getting people transferred is spent waiting while services specific to residents' needs are being developed in the communities. In all, 238 individuals have been involved in the placement project so far. (Of these, the families of 18 individuals subsequently decided to keep

Parents, and Officials from the Hospitals, Community Facilities, and the Department of Social and Rehabilitation Services All Said the New Placement Process Is Superior to Previous Placement Approaches

We contacted officials from a sample of six community facilities. They all said that the individualized placement approach used to transfer hospital residents to the community is preferable to previous approaches, and indicated they were using similar approaches to placing mentally retarded individuals from their communities.

An official from the National Association of State Directors of Developmental Disabilities Services said that the approach is being used increasingly throughout the country. Officials from the Kansas Association of Rehabilitation Facilities also said the individualized approach works.

We also talked to a small number of parent groups and parents of mentally retarded hospital residents who had been placed in the community using this placement approach. The parent groups had very positive opinions of the process. The parents also said they were generally satisfied with community placement and that they believe their family members are happier in the community than they were in the hospitals.

Finally, at least one hospital official said that clients with behavior problems had been placed using this approach that could not have been placed in the community in the past. This official indicated that some clients' behavior problems have actually improved due to their placement in a more appropriate setting.

The focus of the comments from all these groups was that mentally retarded individuals should have the primary say in their placement. There was also general agreement that placements made following this individualized approach would be of a higher quality than was the case previously, and that individuals placed using this approach would be less likely to return to the hospitals.

their family members in the hospital.) A total of 107 hospital residents have been placed in community settings. It took an average of seven months to transfer these individuals from the hospitals to a community setting. The following table shows the approximate amount of time spent on each step of the process.

Time Spent on Each Step in the Placement Process

		Approximate Time (Months)	Proportion of Total Time
Step 1	(developing an Essential Lifestyle Plan and sending completed plan to community facility)	.5	6 %
Step 2	(community facility development of an individual support plan and cost proposal)	4.0	59
Step 3	(cost proposal approved by SRS)	1.0 (a)	13
Step 4	(transition to community)	1.5	22
Total Time		7.0	100 %

(a) Department of Social and Rehabilitation Services officials pointed out that this figure is an average time for all individuals placed in the community since fiscal year 1992. In fact, the time spent on this step has declined each year.

As the table shows, most of the time in the placement process (nearly 60 percent) was spent while the community facilities developed the individualized services the hospital resident needed to be placed in the community.

A total of 113 other hospital residents are still waiting to be placed in a community setting. These individuals have been in the process for an average of about 12 months. Almost all are waiting for services specific to their needs to be developed in the communities (Step 2). We tried to determine if these individuals were more severely disabled than those who had been placed, and found that they were not. Within the timeframe of this audit, we did not have time to explore any other reasons that would explain why this group is taking longer to place.

Developing or "pulling together" individualized community services for a hospital resident can take time. The key to the placement approach being used is the development of individualized services. Thus, when a hospital resident is referred to a community for placement, the community facility has to put together a package that includes all the services and supports the individual needs. Because Kansas has served most of its severely mentally retarded citizens in State hospitals over the years, community facilities have not had to fully develop and maintain all the services needed to serve all levels of disabilities.

The accompanying profile describes a hospital resident who has been placed in the community.

Community Facilities Can Serve Severely Disabled Individuals

We reviewed the case of a hospital resident who had a history of continuing and severe seizures. The individual also exhibited mild behavior problems.

The Essential Lifestyle Plan for this individual listed "non-negotiable items," including time with the family, a quiet environment, and enough space to move around in. Strong preferences also were listed, such as having windows and being able to go for walks. Highly desirable lifestyle elements also were indicated in the Plan. These included such things as going to movies, listening to music, and eating sweets. The Plan also listed those things that had to be done to successfully support the individual, such as talking in a quiet voice, giving the individual plenty of time to respond to questions, understanding the individual's seizure problems, and providing various types of safety equipment.

The meeting on the Plan was attended by hospital and community facility staff and one of the individual's family members.

The community developed a support plan that described how the community facility would serve the individual. It essentially said that the community facility would provide proper supports to allow the individual to fulfill the lifestyle preferences outlined in the Plan. For instance, because the individual enjoys car rides, a vehicle would be provided at the individual's residence. Also, because of the seizure problems, the support plan said that oxygen would be available.

The support plan also indicated the individual would participate in an adult day services program, including recreational and computer activities. The individual would be supervised by one individual during the day. Overnight supervision also would be supplied to monitor the seizure activity. In addition, the individual would have supervision during the evening and early morning hours.

The cost proposal for this individual included the start-up costs needed to outfit an apartment. Examples of such costs included grab bars, adaptive eating utensils, oxygen, and a roll-in shower. The cost proposal also included estimates of direct-care staff time and costs, and day services time and costs. The total annual costs for serving this individual in the community are $46,500, excluding room and board and acute medical costs.

This individual has been placed in the community in an apartment with two roommates. According to the people who work with and supervise the individual, the placement has been successful.

In talking with officials of community facilities and State hospitals and reviewing placement records of hospital residents, we found that some of the services needed are not available at all and would have to be developed. In one case, a community facility said it did not have the specific life-skills services the hospital resident needed. The facility said it would consider developing such services, and suggested that the hospital contact it again in a year.

In some cases, an existing service has to be adapted to meet the needs of a hospital resident. For instance, an apartment might need to be modified to include grab bars. Or a person hired to provide night support for a transferred hospital resident might need special training to deal with the individual's specific disability.

In other cases, the services may already exist in the community. For instance, the hospital resident may need to have an oxygen tank. Even though that service may be readily available within a community, it still has to be arranged for and coordinated with the other services the individual requires.

The next section of the audit examines those factors that tend to increase the time it takes to develop community placements.

Community Centers Primarily Cite Resource Inadequacies As the Reason Why Placements For Hospital Residents Are Not Being Developed as Rapidly as Anticipated

Nothing requires a community facility to serve a hospital resident; however, the community officials we talked with were supportive of the State's efforts in this area. Nevertheless they cited a number of factors that tend to increase the time it takes to develop placements for hospital residents.

The community mental retardation centers do not have full-time staff who are devoted to developing hospital placements. The community facility staff who develop placements for hospital residents also are responsible for working with their facilities' existing clients, as well as with mentally retarded individuals from their communities. Because they have other responsibilities, these staff may take more time to develop placements for hospital residents than if they devoted all their attention to such placements.

Officials from the community facilities also noted that the placement project does not provide any funding to reimburse them for the time they spend developing support plans.

Community facilities told us the reimbursements they receive are insufficient to cover all the costs of serving hospital residents in the community, although Department officials said the funding provided generally should be adequate. Generally, when hospital residents are transferred to community settings, their placements and services are funded with Medicaid-waiver money. In addition, the 1993 Legislature appropriated $425,000 for community facilities to pay for start-up costs associated with placing hospital residents in community settings.

Officials from five of the six community facilities we contacted, as well as the official from the Kansas Association of Rehabilitation Facilities, expressed the following concerns about the inadequacy of funding:

- They said the State does not fully reimburse start-up and on-going operational costs associated with the transferred hospital client, and that no funds are available to reimburse the facilities for staff time required to meet the hospital resident, develop a support plan, and the like. They also said the State does not always want to fund the level or intensity of services called for in the support plan. The result of these problems is that the community facilities end up subsidizing the hospital residents out of their other resources.
- Officials from two community facilities also said some services, such as transportation and dental services, are not funded through the Medicaid waiver so the community facility may have to subsidize these expenses.

We spoke with Department officials about these issues, and they had the following comments:

- They told us that it has been a struggle going from a grant process to an individualized fee-for-service process, but that community facilities are getting better at establishing rates for community placement of hospital residents. They said the financial conditions of the community facilities generally are steadily improving. Department officials acknowledged that, in some cases, the start-up grants may not cover all the costs incurred to place the hospital resident. They noted, however, that in other cases the start-up grants more than covered start-up costs, and that the facilities retained these dollars for their own use.

- Department officials also said they try to work with community facilities as they develop cost proposals. We reviewed Department files of a sample of hospital residents who had been placed in the community to see what efforts have been made in this area. In one situation in which three individuals were roommates, the Department found that the community facility would receive more money overall if it accepted "tiered" rates for these individuals instead of individualized rates (tiered rates are per-diem rates established on the basis of disability scores). The Department gave the community facility the option of using the tiered rates.

  In another instance, a community facility sent a cost proposal that the Department thought was too expensive and provided for an unjustified level of staffing. The Department offered to hire a nationally recognized consultant to review the case and prepare an independent service plan and cost proposal for this resident. The Department agreed to abide by the consultant's proposal. The community facility apparently did not accept this offer, but has since submitted another proposal that is less expensive than the first. The second proposal was under review at the time of this audit.

The community facilities also said that, in some cases, the State agreed to a particular rate, then reduced the rate after the placement had been made. Department officials said that, in one recent instance, a community facility was being paid individual rates for a hospital resident it had placed. When the resident's case had its annual review, the rates were dropped so that the facility would no longer receive the higher, individual rates, but would receive lower, tiered rates.

Department officials said the lower rates had been established by the individual's case manager, who works for the community facility, and that they did not know that the rates had been dropped. The Department has since restored the facility's original, higher rates.

Because of limited resources and existing community needs, services may be developed to meet the needs of mentally retarded people from within the communities first. Community facilities maintain primary and secondary waiting lists of mentally retarded individuals who apply to them for services. This information is reported to and entered into the Kansas Rehabilitation Information System. The primary list consists of those individuals who want immediate services. The secondary list consists of those individuals who want services at some time in the future, but not necessarily immediately. An example of someone who might be on a secondary waiting list would be a child who is in the public school system. That child most likely would not need services until he or she gets out of high school.

As of January 1, 1994, there were 813 individuals on the community facilities' primary waiting lists, and 508 on the secondary waiting lists. In our interviews with community facility officials, we learned that, in some cases, mentally retarded individuals had been on these waiting lists for several years. Appendix C presents the number of individuals on waiting lists for services, by community facility.

Community facility staff develop services for both hospital residents and people from their communities. Because some of the people from their communities have been on the waiting list for services for years, there is pressure to develop services for those individuals before serving hospital residents. And, when openings occur for specific services, such as a sheltered workshop, there again is pressure to fill the opening with someone from the community waiting list first.

Department of Social and Rehabilitation Services officials noted that because the hospital residents have their own sources of funding, at least the competition for dollars is minimized.

Other Factors Tend to Slow the Placement Process Down

We identified a number of factors in the way the process itself is implemented that appeared to create some potential bottlenecks in transferring hospital residents to community settings.

Officials of the community facilities said they are not involved early enough in the placement process, although hospital officials said they are invited to initial planning meetings. Community mental retardation officials told us that sometimes they do not know anything about the hospital resident they are being asked to place until they have received an Essential Lifestyle Plan from the hospital. They said this lack of early involvement creates several problems:

- it is critical to get to know the hospital resident before they can develop a support plan; this takes time.
- if they are not involved as the Essential Lifestyle Plan is being developed, sometimes unrealistic expectations about what services the community can provide may be developed.

The placement project process requires the State hospitals to invite community facilities to attend Essential Lifestyle Plan meetings. We talked with hospital officials who said they had contacted community facilities by phone to invite them to attend these meetings. These officials told us that community facility officials do not always attend.

Community facilities may not always be aware of possible referrals. In our interviews with community facilities, one said it had not gotten any referrals. The facility was involved in placing hospital residents, but the officials we spoke with said they had initiated the placements themselves. Another facility indicated that communication problems, since cleared up, had hampered the referral process.

In March 1993, the Department of Social and Rehabilitation Services conducted a survey of community facilities. Three of 12 agencies responding to a question about why they had not placed any hospital residents in the last three months said they had not received any referrals from the hospitals.

The Department has established some procedures that should help minimize these problems. Since the fall of 1993, it has been working to provide information to community facilities about hospital residents who may be interested in being served in the community. A Community Information Sheet is sent, with the approval of the hospital resident's parent or guardian, to community facilities to inform them about which individuals from their areas are in the State hospitals, and to determine whether there is any interest in having the hospital resident served in the community.

In addition, the Department's placement manual requires hospitals to refer 1.5 hospital residents for every resident who must leave to meet their population-reduction goals. The purpose of this requirement is to help ensure that adequate placements to community facilities will be made. It should also help ensure that adequate referrals are made.

Even though this requirement exists, we found that hospitals are not consistently following it. One hospital official told us that because hospital residents who already have been referred are not being placed quickly, referring more people compounds that problem. The official said that parents and guardians become frustrated with the long wait for placement, and indicated that this created credibility problems not just for the hospital, but for the whole service delivery system.

The hospitals and the Department are not always following up with community facilities that do not respond to a referral or reject it. In reviewing the time residents spent on each step of the placement process, we noticed that in a number of cases, more than one community provider had to be contacted before a client was accepted. Often, the tracking records indicated a several-month delay between referrals. We asked hospital officials what they did to follow-up on referrals, and found that, until recently, no systematic procedures were in place to ensure that follow ups were made on timely basis.

The Department's placement manual now requires that hospital staff make monthly follow-up contacts with community facilities, and enter information about the contacts into a centralized database of hospital referral information. The manual also requires Department officials to provide a summary of the data every three months to the Commissioner of Mental Health and Retardation Services, the State hospitals, and the community facilities.

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The Department has recently revised its computerized tracking of hospital residents who are participating in the placement project to enable its staff to do the required data summaries. Although the system had not been in place long enough for us to assess whether these activities were being conducted as required, at least procedures are now in place to address this issue.

The Original Hospital Population-Reduction Goals May Have Been Optimistic

According to an official with the National Association of State Directors of Development Disabilities, other states are beginning to use a similar approach to transferring hospital residents to community facilities. We reviewed a study that had been conducted on Maine's experience in this area. Maine is moving towards the development of a totally community-based system for providing services to its mentally retarded citizens. Underlying that movement is the belief that "the essence of community living is being able to determine one's life style."

Maine has been expanding its use of the Medicaid waiver to develop individual community-placement plans for hospital residents. The state has transferred hospital residents at the rate of about one per week. On average, those transfers take nine months to complete. Maine officials have said they do not expect the rate of transfer to change over the next few years.

Kansas has transferred 40 to 50 hospital residents each year under the new placement approach. This placement rate has been fairly stable. Placements so far have taken an average of seven months to complete. These figures are consistent with Maine's experience, and they suggest the higher rate of placement required to meet the population-reduction goals may have been optimistic.

Department of Social and Rehabilitation Services officials told us that they think the goals are reasonable, and that as community facilities gain experience with developing individualized plans and learn who they can serve from the hospitals, the number of placements will increase. However, given Maine's experience, the current rate of placement may be about the rate that should be expected.

Per-Person Costs for Community Placements May Be Less Than Per-Person Hospital Costs

We also were asked to look at how the cost per person for community placements compared with costs per person in State hospitals. The comparisons are not easy to make because hospital and community settings are not comparable. For instance, because of their fixed costs, hospital costs per resident will necessarily increase as populations are reduced. Also, hospital costs include expenditures for room, board, and medical care. Such expenditures represent a significant cost of community care and they need to be accounted for.

The following table compares the costs of serving individuals in hospitals with the costs of serving individuals in community settings. The hospital cost figure is an average annual cost for all hospitals.

The community costs are for individuals who have transferred from State hospitals to community settings. We also estimated medical expenditures, such as doctor and hospital visits, and room and board expenditures.

Average Annual Cost
Per Individual
Fiscal Year 1994 (est.)

Hospital		**$84,848**
Community:		
room and board	$5,352 (a)	
medical expenses	$1,232 (b)	
Medicaid waiver	$43,294	
Community Total		**$49,878**
Difference		**$34,970**

(a) These residents pay for their own room and board. Because most of these individuals receive Supplemental Security Income of $5,352 per year, we used that figure as an estimate of room and board expenditures.

(b) Medical expenses are paid for out of regular Medicaid dollars. This figure comes from a report to the federal government that indicates the medical expenses for those hospital residents receiving home- and community-based services paid for with the Medicaid waiver.

Even though the cost of serving mentally retarded individuals in the community is less than serving such individuals in State hospitals, the State will not realize any significant total cost savings until one or more of the State hospitals are closed. That is because, despite reductions in populations, total State hospital costs are not going down. The main factor causing this is that, as long as a hospital is operating at all, it will have a significant amount of ongoing costs for basic administration, maintenance, and patient care.

To see what kinds of savings might be possible if one of the State's mental retardation hospitals were closed, we compared the cost of serving mentally retarded people in the State hospitals with what it would cost to serve those same people in the community. That information is shown in the table on the following page.

As the table shows, if all the mental retardation hospital residents were served in the community and the hospitals were closed, the savings would range from about $6.4 million at Parsons State Hospital to more than $12 million at Winfield State Hospital.

Even though the costs of serving each individual in the community may, on average, be less than serving individuals in State hospitals, the total cost of serving mentally retarded individuals may increase as more community services become

Potential Average Annual Savings
If Hospital Residents Were Served
in Community Settings
Fiscal Year 1994 (est.)

	Kansas Neurological Institute (291 clients)	Parsons State Hospital (240 clients)	Winfield State Hospital (310 clients)
Hospital expenditures (These are the costs of serving the residents currently in the hospital.)	$25,004,485	$18,459,642	$27,892,911
Community expenditures (These are the estimated costs for serving those same residents in the community.)	14,514,521	11,970,739	15,462,205
Potential Savings	$10,489,964	$6,488,903	$12,430,706

available and as the Medicaid waiver is increasingly used to serve individuals in the community. One potentially mitigating factor noted by Department of Social and Rehabilitation Services officials is that as individuals adapt to community living, the supports they require will be reduced. For instance, they said that instead of a full-time job helper to support a client in a community work setting, co-workers will be able to provide some of those supports. Similarly, friends and neighbors may be able to provide some transportation services. The officials suggested that the costs of community care may decrease over time because of such factors.

Conclusion

The placement approach adopted by the Department is supported by all those involved in the process. It focuses on the needs and desired lifestyle of the individual and appears most likely to result in high-quality, successful placements of hospital residents in community settings. It also appears to be an approach that will permit hospital residents with all levels of disabilities to be served in the community. However, by its nature the approach is time-consuming. When the process was first implemented, there were some initial start-up problems that may have slowed the rate of transfers down, but it appears that many of these problems have been addressed. Despite these improvements, the evidence suggests that the rate of placements may not increase dramatically because of the placement approach being used, and because of the other factors that can limit the rate of transfers of hospital residents to community settings. As a result, the State may not be able to meet the hospital population-reduction goals it has set for itself in the timeframe established.

Not meeting these goals has a number of implications. First, authorized hospital staffing levels have been reduced in anticipation of meeting these goals. If this trend were to continue, the State hospitals eventually would run the risk of being decertified because of inadequate staffing. Ultimately, the State could lose Medicaid dollars or be faced with authorizing new staff to meet staffing requirements. According to Department of Social and Rehabilitation Services officials, no reductions in staffing are planned for fiscal year 1995.

The other implication of not meeting the population-reduction goals within the established timeframe is that the short-term cost of transferring hospital residents to the community becomes much higher. As noted earlier, State expenditures for the hospitals have not dropped dramatically, even though staffing levels and populations are being reduced. In fact, not until one of the hospitals is closed will the State realize any significant cost savings. The longer it takes to reduce hospital populations, the longer the State will incur both the cost of hospitals and the cost of community care.

Recommendations

1. The Department of Social and Rehabilitation Services and the State mental retardation hospitals should continue their efforts to improve the process for transferring individuals from State mental retardation hospitals to community settings by doing the following:

   a. Ensure that Department, hospital, and community facility staff have on-going training in the placement process so that it is carried out consistently and as efficiently as possible.

   b. Ensure that the State mental retardation hospitals invite all interested parties, including the community service providers, to the lifestyle planning meetings. The hospitals also should make every effort to ensure that community facilities are involved in planning for hospital residents' community placements.

   c. Ensure that community facilities are aware of those hospital residents who are interested in being placed in their areas. Hospital staff should make regular contacts with community facilities to share up-to-date information on those residents who have expressed an interest in community placements.

d. Ensure that the hospital staff make the required monthly contact with the community facility that has been given a referral. As appropriate, the hospital staff should document and take actions to address any problems that are slowing down the transfer of the individual from the hospital.

2. The Department should review the established population-reduction goals to determine whether they should be modified to reflect the actual speed of community placements. It should provide the Legislature with any modifications so that legislators can be better informed about a realistic timeframe for potentially closing a State mental retardation hospital.

3. Because the cost of operating three State mental retardation hospitals while hospital populations are being reduced is so high, the Department and the Legislature should consider whether the State should move more quickly to close one of the mental retardation hospitals, perhaps through a consolidation of the existing facilities.

APPENDIX A

Population Movement at the Three State Mental Retardation Institutions
Fiscal Years 1991 through Mid-1994

Kansas Neurological Institute

	Fiscal Year				
Type of Movement	**1991**	**1992**	**1993**	**1994** (Through Dec.)	**Total**
+Admissions	2	2	0	0	+4
+Re-Admissions	2	0	0	0	+2
+Placement Returns	2	0	1	0	+3
-Direct Discharges	0	-1	0	0	-1
-Deaths	-4	-9	-2	0	-15
-Community Integration Project Placements Identified by KNI	0	-19	-13	-8	-40
-Other Placements	-15	-9	0	-1	-25
Change in Resident Population from Previous Year	-13	-36	-14	-9	-72 (a)

Parsons State Hospital and Training Center

	Fiscal Year				
Type of Movement	**1991**	**1992**	**1993**	**1994** (Through Dec.)	**Total**
+Admissions	20	27	2	1	+50
+Re-Admissions	5	5	1	1	+12
+Placement Returns	6	15	8	2	+31
-Direct Discharges	-4	-3	-4	-5	-16
-Deaths	-1	0	0	-1	-2
-Community Integration Project Placements Identified by Parsons	0	0	-15	-9	-24
-Other Placements	-40	-30	-13	-3	-86
Change in Resident Population from Previous Year	-14	14	-21	-14	-35 (a)

Winfield State Hospital and Training Center

	Fiscal Year				
Type of Movement	**1991**	**1992**	**1993**	**1994** (Through Feb.)	**Total**
+Admissions	4	2	1	0	+7
+Re-Admissions	2	3	3	5	+13
+Placement Returns	4	2	1	0	+7
-Direct Discharges	0	0	-1	0	-1
-Deaths	-9	-8	-8	-4	-29
-Community Integration Project Placements Identified by Winfield	0	-24	-11	-8	-43
-Other Placements	-24	-8	-3	0	-35
Change in Resident Population from Previous Year	-23	-33	-18	-7	-81 (a)

(a) The total for all three hospitals will not agree with the "State Hospital Population Changes" chart on page 11 of this report because of inconsistencies in the way the data was reported to us by the hospitals.

APPENDIX B

Population Reduction Goals Compared to Actual Population Fiscal Years 1991 through Mid-1994

Kansas Neurological Institute

	Fiscal Years			
	1991	1992	1993	1994
Year-End Population Goals	333	310	282	247
Actual Population	350	314	300	291 (a)
Difference	-17	-4	-18	-44

Parsons State Hospital and Training Center

	Fiscal Years			
	1991	1992	1993	1994
Year-End Population Goals (b)	270	270	242	227
Actual Population	260	273	254	240 (a)
Difference	10	-3	-12	-13

Winfield State Hospital and Training Center

	Fiscal Years			
	1991	1992	1993	1994
Year-End Population Goals	362	332	304	269
Actual Population	371	336	320	310 (a)
Difference	-9	-4	-16	-41

(a) This figure is actual population as of December 31, 1993.

(b) Parsons State Hospital did not begin participating in the community integration project until mid-1992, so no formal population-reduction goals were established for this hospital in fiscal years 1991 and 1992.

Kansas Rehabilitation Information System
Community Mental Retardation Centers
Primary Waiting List

As of January 1, 1994

AGENCY	Individual Count	Day Only	Residential Only	Day and Residential	Other Programs	Children's Programs
Achievement Services	0	0	0	0	0	0
Big Lakes Dev. Center	3	0	1	2	0	0
Brown County Dev. Services	10	1	3	6	0	0
COF Training Services	7	2	2	3	0	0
Cerebral Palsy Research	50	1	46	3	0	0
Class LTD.	34	5	5	22	2	0
Cottonwood, Inc.	36	7	7	22	0	0
Cowley County Dev. Services	19	5	1	13	0	0
Developmental Svrs. of NW Kansas	46	1	5	29	5	6
Futures Unlimited	10	2	3	4	1	0
Goodwill Industries	8	8	0	0	0	0
Johnson Co. Mental Retardation Ctr	101	8	55	38	0	0
Kansas Elks Training Center	134	19	53	55	7	0
Lakemary Center	33	0	32	1	0	0
McPherson Co. Div. Services	19	0	13	6	0	0
Nemaha Co. Training Center	4	2	1	1	0	0
Northview Dev. Services	26	4	4	18	0	0
Occupational Ctr. of Central Kansas	21	9	6	5	1	0
STEPS/Penningtons	23	1	5	15	2	0
Rainbows Unlimited	63	0	0	0	0	63
Sheltered Living, Inc.	161	0	156	0	5	0
Southwest Dev. Services, Inc.	23	2	2	19	0	0
Starkey Devopmental Center	77	12	20	45	0	0
Sunflower Diversified Services	12	1	1	8	2	0
Topeka Assn. for Retarded Citizens	29	29	0	0	0	0
Trng. & Eval. Ctr. for Handicapped	33	12	6	15	0	0
Terramara	8	0	0	6	2	0
Tri-Ko, Inc.	24	4	6	14	0	0
Tri-Valley Dev. Services	4	1	0	3	0	0
Wyandotte Dev. Dis. Services	71	43	9	14	5	0
SUBTOTAL	1089	179	442	367	32	69
Duplicate applications	90	5	7	76	2	0
CURRENTLY SERVED IN:						
Private ICF/MH	22	4	8	10	0	0
Private Large ICF/MR	50	1	14	35	0	0
Private Nursing Facility	16	1	10	5	0	0
Private Small ICF/MR	18	2	10	6	0	0
State MH Hospital	17	1	1	15	0	0
State MR Hospital	63	4	32	27	0	0
TOTALS (Not currently served)	**813**	161	360	193	30	69

Note: Individuals are placed on the primary waiting list if they or their family would immediately accept services if they were offered.

APPENDIX C

This appendix contains the Primary and Secondary Waiting Lists for Community Mental Retardation Centers, as of January 1, 1994. Individual are placed on the Primary Waiting List if they or their family would immediately accept services if they were offered. Individuals are placed on the Secondary Waiting List if they or their families would not immediately accept services if they were offered. This information is maintained in the Kansas Rehabilitation Information System.

Kansas Rehabilitation Information System
Community Mental Retardation Centers
Secondary Waiting List
As of January 1, 1994

AGENCY	Individual Count	Day Only	Residential Only	Day and Residential	Other Programs	Children's Programs
Achievement Services	18	3	6	9	0	0
Big Lakes Dev. Center	19	0	15	4	0	0
COF Training Services	7	3	1	3	0	0
Cerebral Palsy Research	8	0	7	1	0	0
Class LTD.	13	2	3	7	1	0
Cottonwood, Inc.	20	0	9	11	0	0
Cowley County Dev. Services	8	0	0	7	1	0
Developmental Srvs. of NW Kansas	107	11	14	75	5	2
Futures Unlimited	1	0	1	0	0	0
Help, Inc.	2	0	0	2	0	0
Johnson Co. Mental Retardation Ctr.	91	18	39	34	0	0
Kansas Elks Training Center	7	3	0	4	0	0
Lakemary Center	46	0	43	3	0	0
McPherson Co. Div. Services	0	0	0	0	0	0
Nemaha Co. Training Center	2	0	2	0	0	0
Northview Dev. Services	29	2	9	18	0	0
Occupational Ctr. of Central Kansas	37	11	5	21	0	0
STEPS/Penningtons	1	0	0	1	0	0
Rainbows Unlimited	0	0	0	0	0	0
Sheltered Living, Inc.	36	0	36	0	0	0
Southwest Dev. Services, Inc.	53	1	2	48	2	0
Starkey Developmental Center	87	4	34	49	0	0
Sunflower Diversified Services	24	0	10	13	1	0
Topeka Assn. for Retarded Citizens	16	16	0	0	0	0
Trng.& Eval. Ctr. for the Handicapped	20	2	5	13	0	0
Terramara	6	0	0	5	1	0
Tri-Valley Dev. Services	4	1	2	1	0	0
Wyandotte Dev. Dis. Services	4	2	2	0	0	0
SUBTOTAL	666	79	245	329	11	2
Duplicate applications	61	0	7	53	1	0
CURRENTLY SERVED IN:						
Private ICF/MH	5	1	0	4	0	0
Private Large ICF/MR	36	1	4	31	0	0
Private Nursing Facility	7	0	4	3	0	0
Private Small ICF/MR	5	1	1	3	0	0
State MH Hospital	12	1	1	10	0	0
State MR Hospital	32	0	4	28	0	0
TOTALS (Not currently served)	508	75	224	197	10	2

Note: Individuals are placed on the secondary waiting list if they or their family would not immediately accept services if they were offered.

Appendix D

Agency Responses

On March 14, we provided copies of the draft audit report to the Department of Social and Rehabilitation Services. Its responses is included in this appendix.

The Department also provided us with a separate listing with suggestions for corrections or clarifications. We carefully reivewed this list as well, and made a few changes to improve the accuracy and clarity of the report. However, these changes did not alter any of the findings or conclusions of the report. This listing is available for review in the Division's offices.

On April 15, we provided a copy of the draft audit report to the Kansas Association of Rehabilitation Facilities. Its response also is included in this appendix.

JOAN FINNEY, GOVERNOR OF THE STATE OF KANSAS

KANSAS DEPARTMENT OF SOCIAL
AND REHABILITATION SERVICES
DONNA WHITEMAN, SECRETARY

RECEIVED
MAR 24 1994
LEGISLATIVE POST AUDIT

March 23, 1994

Barbara J. Hinton
Legislative Post Auditor
Legislative Division of Post Audit
Merchants Bank Tower
800 S.W. Jackson, Suite 1200
Topeka, KS 66612-2212

Dear Ms. Hinton:

On behalf of the Kansas Department of Social and Rehabilitation Services (SRS) thank you for the opportunity to analyze the performance audit report reviewing the placement of persons with mental retardation or other developmental disabilities (MR/DD) from state hospitals to community service settings. SRS believes this is an excellent report demonstrating an impressive grasp of the issues in an extremely complex area. This audit report provides a foundation to enhance everyone's understanding of the successes of the person centered placement process.

We are pleased the audit supports the person centered placement process and the partnership of the Community Mental Retardation Centers, State MR Hospitals, and MR/DD Services begun in 1991. The goal of the process was to develop a transition model from institution to community services through a four-way partnership with families and the individual to be served constituting the primary partner. The purpose was to provide individuals residing in State MR Hospitals with community lifestyles of their choice through adequate supports funded with sufficient resources. The responsibility for success was to rest on the MR/DD system, not the individual, and anyone permanently returned to an MR Hospital from a community setting would be a failure of the system's partners rather than the individual.

The process begins in the State MR Hospital when a person centered Essential Lifestyle Plan (ELP) is developed by parents, the individual, community agency staff, and MR Hospital staff which outlines the needs, wants, and desires of the individual. It then becomes the responsibility of the local community agency to operationalize the ELP into an individualized support plan. This plan, based upon the choices made in the ELP, details the services and supports necessary to assure a successful community placement. Concurrently, the community agency develops a cost proposal which indicates the financial support needed for the implementation of the services and supports planned. The individual support plan and cost proposal are then discussed with the referring MR Hospital and forwarded to Mental Health and Retardation Services to determine whether additional review is needed or final approval is warranted.

When all plans have been approved, tentative move dates are set, and the community agency, the individual and parents arrange all the conditions necessary to support the lifestyle chosen through the placement process.

As the placement process evolved, the rate of placements occurring indicated a need to revisit and smooth the transfer process. SRS is pleased the audit supports the efforts which have been undertaken by the partners to make the placement process more efficient. Some of these efforts are:

* An independent assessment of the process completed by Rucker, Powell and Associates which provided many valuable recommendations.

* MH&RS employing and assigning an experienced staff person to support the MR Hospitals and community agencies in the placement process.

* Scheduling statewide meetings of staff from MR Hospitals and community agencies to formulate the outlines of a placement manual to streamline the placement process.

* Developing an Information Sheet formalizing a parent contact and waiting list procedure as the first step in involving community agencies much earlier in the placement process.

* Using an up-front "start-up" grant procedure with funds appropriated from the legislature which is extremely flexible in support of the individuals and the agencies involved in the transfer process.

* The Commissioner of MH&RS meeting with key participants at all levels of the placement process seeking recommendations for improving the current process and suggestions for creative new opportunities which could accelerate transfers to the community.

While it is natural to focus on how quickly placements are made and to make every effort to improve and streamline the process, we must

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remember there is a great deal to celebrate in what has been accomplished through the person centered placement process.

- More than 137 individuals, including children in supported family living homes, have been placed and supported in community settings consistent with their chosen lifestyles.
- The quality and satisfaction with these services is high.
- The placement process is family friendly and family directed.
- The placements have given individuals an opportunity for full participation in the community.
- Very few individuals have been returned to the hospitals from their community settings.
- The new process has been an impetus for changes in the lives all people with MR/DD.
- These placements have **not** been at the expense of serving many more people from community waiting lists.
- The measured types and severity of the disabilities of the individuals placed into community settings appears similar to the disabilities of those still living in state hospitals.

These successes have resulted in achieving some secondary operational and budgetary goals including:

- The number of people served in state hospitals has declined significantly.
- Admissions to state hospitals have all but ceased with little known hardship.
- Reductions in the size of state hospitals and increases in community services have occurred without court orders or consent decrees experienced in many other states.
- Kansas is once again being looked to for leadership in services to individuals with MR/DD.

Everyone associated with the process should be rightfully proud of what has been accomplished thus far. We are confident much more can be done. This was accurately described in the audit report. Because of this SRS has only one major concern regarding the audit report:

* An evaluation of the placement goals should be made only after a thorough review of the experiences of more states than were presented in the audit report. Maine has half the population of Kansas and only one State MR/DD hospital from which to place individuals.

The independent evaluation of the placement project done earlier by Rucker, Powell and Associates may have said it best:

> But why does this process seem so difficult, so complicated? Because, in fact, it is. The CID project is calling for no doubt the greatest transformation in the history of Kansas mental retardation services... Planning individual transitions consistent with project values represents multiple layers of shifts in thought of how the State supports individuals with mental retardation... Since the CID project is breaking new ground for both the system and individual, it is far more difficult but it also has far greater potential for positive changes.

SRS is pleased the audit report accurately captures the difficulty of the process as well as the great benefits it presents to those with MR/DD in Kansas.

Thank you for this opportunity to comment on the report.

Sincerely,

Donna L. Whiteman
Secretary

DLW:GDV:RS:eb

Kansas Association of Rehabilitation Facilities
Jayhawk Tower • 700 Jackson • Suite 212 • Topeka. Kansas 66603-3731
(913) 235-5103 • Fax (913) 235-0020

April 18, 1994

Barbara J. Hinton
Legislative Post Auditor
800 SW Jackson
Topeka, Kansas 66612 - 2212

Dear Ms. Hinton:

The Kansas Association of Rehabilitation Facilities (KARF) represents a membership of 42 not-for-profit corporations across Kansas providing community based services for persons with developmental disabilities. The Association and its members provided information to Legislative Post Audit staff to assist them in the performance audit of the process of transferring patients from State institutions to community facilities.

The audit report accurately describes the history of the process for transferring persons with developmental disabilities from State hospitals to community facilities. It also accurately depicts our members' broad support for the community integration program.

We generally agree with the auditors' conclusions and their recommendations to the Legislature, except where noted in the attachments to this letter.

We appreciate the opportunity to review this report and respectfully request that the committee consider our comments and suggestions. If you or the post audit staff have any questions or require additional clarification, please feel free to contact me or Martha Hodgesmith, Associate Director of KARF.

Very truly yours,

Tom Laing

Tom Laing
Executive Director

The following points are in response to the performance audit report, <u>Reviewing the Transfer of Mentally Retarded Patients from State Institutions to Community Living Facilities</u>.

1. Concluding that SRS is phasing-out large ICF/MRs (page 4) is not supported by any recent actual bed reductions or facility closures. Most ICF/MR bed reduction has come from community facilities converting small bed (less than 15 beds) facilities to individualized services.

2. The report's analysis of the sources of funding for community services (page 8) does not include county mill levy funding. Information on that funding is found in ATTACHMENT I.

3. The charts on pages 7, 8, and 9 do not provide a comparison of the numbers of persons served to the money spent. Fewer people are being served in institutional settings, yet the costs have remained relatively constant.

   6351 adults are served with MR/DD funding. Of that population, 1802 adults (28%) reside in institutional settings which are supported by 62.1% of the funding. The remaining 4549 adults (72%) receive community services supported by 37.9% of the funding. ATTACHMENT II

   The national trend according to <u>Braddock, et.al</u> is that 51% are living in community settings supported by 56% of the MR/DD funding.

4. The report indicates (page 18) that Kansas has served most of its severely retarded citizens in state hospitals and thus community facilities have not had to fully develop and maintain all services needed to serve all levels of disabilities. This suggests a potential cause for placement delays. This is somewhat misleading. As community programs have been asked to serve those with more severe disabilities, they have developed the community services to match the needs. Delays result not from a lack of experience, but from the lack of available resources to establish services.

   As noted in Attachment III, the profile of those served in the community is a fairly true reflection of those served in state institutions.

   See ATTACHMENT III - **WHO RECEIVES SERVICES - MHRS DIVISION OF MR/DD 1993 ANNUAL REPORT** (pp. 14-17) and **AN ANALYSIS OF PROFILES OF INDIVIDUAL CHARACTERISTICS OF PERSONS WITH DEVELOPMENTAL DISABILITIES - JULY 1993** (pp. 21-23)

(Comments submitted in response to the draft report of the Legislative Post Auditors entitled Reviewing the Transfer of Mentally Retarded Patients from State Institutions to Community Living Facilities, continued).

5. The chart which is titled **Average Annual Costs Per Individual** (page 25) does not reflect:
   a. medicaid costs for medical care provided to institutional residents when such care is received outside the institution.
   b. nongovernmental funds used by community facilities to subsidize consumer costs in excess of the average individual monthly income of $446. Such costs include medical care not covered by the medical card, rent, utilities, food, transportation and other basic costs of living.

6. It is true and it remains a serious problem that community facilities are not reimbursed for the costs of a majority of the ELP planning effort. Considering that all "players" (consumers, guardians, families, institutional staff and community staff) must be involved for the ELP development to result in successful community placements, it is crucial that SRS reimburse community staff for the time and expenses involved in the ELP process.

   We would urge the committee to consider this recommendation and make it a part of their findings. Adequate reimbursement is crucial to viable ELP planning and implementation.

Attachment I

Social and Rehabilitation Services
Mental Health and Retardation Services
History of County Mill Levy Support for Community MR/DD Services
For Years 1991-1994
As Reported By Community Mental Retardation Agencies

		1991	1992	1993	1994
Achievment	Atchison	$45,000	$45,000	$45,000	$45,000
Arrowhead	Barber	$64,878	$64,878	$64,878	$64,878
	Clark	$15,789	$16,263	$16,263	$16,263
	Commanche	$9,331	$10,000	$10,500	$10,500
	Edwards	$23,538	$25,235	$25,235	$25,235
	Ford	$132,000	$135,900	$137,260	$137,260
	Gray	$31,500	$32,760	$32,760	$32,760
	Harper	$50,000	$50,000	$50,000	$50,000
	Hodgeman	$8,500	$8,500	$9,000	$9,000
	Kingman	$64,306	$62,552	$62,552	$62,552
	Kiowa	$28,000	$28,000	$28,000	$28,000
	Meade	$26,064	$28,663	$29,139	$29,139
	Ness	$16,727	$17,000	$17,000	$16,000
	Pratt	$68,488	$72,512	$72,512	$72,512
Big Lakes	Clay	$31,704	$32,642	$34,818	$36,559
	Geary	$55,565	$51,570	$51,570	$54,149
	Pottawatomie	$199,379	$203,381	$204,311	$214,526
	Riley	$116,875	$128,264	$123,133	$125,000
Brown Co.	Brown	$19,400	$28,476	$28,476	$28,476
COF	Franklin	$53,076	$59,229	$53,091	$62,973
	Coffey	$130,443	$129,098	$129,346	$125,517
	Osage	$15,316	$15,168	$12,618	$15,456
Class	Cherokee	$39,300	$39,312	$39,312	$48,228
	Crawford	$75,000	$102,650	$102,650	$123,825
	Labette	$47,080	$48,703	$48,703	$54,848
	Montgomery	$157,621	$159,540	$157,190	$157,297
Cottonwood	Douglas	$236,900	$236,900	$236,900	$314,150
	Jefferson	$45,000	$45,000	$45,000	$50,000
Cowley Co.	Cowley	$96,790	$97,324	$96,676	$112,000
DSNWK	Cheyenne	$12,627	$12,416	$12,869	$12,817
	Decature	$15,130	$18,260	$25,000	$24,014
	Ellis	$153,669	$175,348	$184,115	$191,948
	Gove	$39,454	$40,716	$45,000	$43,396
	Graham	$71,501	$71,241	$71,745	$74,647
	Logan	$18,688	$18,212	$20,000	$12,858
	Norton	$53,975	$55,621	$53,000	$53,735
	Osborne	$12,256	$12,375	$12,400	$8,744
	Phillips	$22,904	$21,677	$20,019	$22,264
	Rawlins	$30,804	$32,710	$40,050	$36,500
	Rooks	$38,977	$49,132	$51,000	$34,877
	Russell	$72,511	$128,498	$129,000	$126,178
	Sheridan	$24,222	$26,000	$24,200	$23,162
	Sherman	$26,027	$29,973	$30,000	$31,906
	Smith	$22,914	$21,388	$22,250	$22,087
	Thomas	$44,867	$48,798	$70,170	$33,519
	Trego	$15,706	$32,709	$31,875	$23,354
	Wallace	$11,824	$11,589	$12,076	$14,684
Futures	Summer	$127,632	$127,632	$127,731	$128,172
Help	Leavenworth	$90,000	$100,000	$100,000	$100,000
Hetlinger	Lyon	$8,770	$8,770	$8,770	$4,400
JCMRC	Johnson	$1,558,852	$1,584,803	$1,622,199	$2,226,696
McPherson	McPherson	$114,939	$114,939	$117,454	$127,028
Nemaha Co.	Nemaha	$57,000	$60,517	$60,517	$65,459
Northview	Harvey	$93,000	$93,000	$93,000	$93,000
	Marion	$36,169	$36,707	$39,000	$39,471

Social and Rehabilitation Services
Mental Health and Retardation Services

History of County Mill Levy Support for Community MR/DD Services
For Years 1991-1994
As Reported By Community Mental Retardation Agencies

		1991	1992	1993	1994
OCCK	Cloud	$61,367	$68,461	$68,461	$70,461
	Dickinson	$52,000	$52,000	$81,000	$81,000
	Ellsworth	$42,300	$42,300	$42,300	$43,992
	Jewell	$6,775	$8,650	$9,650	$9,650
	Lincoln	$0	$2,000	$2,000	$3,000
	Mitchell	$30,041	$32,823	$33,823	$33,823
	Ottawa	$23,185	$25,444	$25,444	$21,552
	Republic	$40,500	$40,500	$40,500	$42,120
	Saline	$223,500	$230,205	$230,205	$256,413
SDSI	Finney	$155,000	$202,800	$202,800	$202,800
	Grant	$58,000	$38,750	$38,750	$46,750
	Greeley	$14,000	$12,500	$15,000	$15,000
	Hamilton	$31,000	$23,000	$39,750	$39,750
	Haskell	$20,000	$23,000	$26,000	$26,000
	Kearny	$44,000	$36,000	$49,750	$49,750
	Lane	$35,000	$30,000	$30,000	$30,000
	Morton	$35,000	$26,500	$31,000	$31,000
	Scott	$20,000	$19,500	$19,500	$19,500
	Seward	$60,000	$62,000	$62,000	$78,000
	Stanton	$31,000	$23,500	$25,250	$25,250
	Stevens	$60,000	$71,500	$71,500	$95,750
	Wichita	$26,000	$13,000	$13,750	$13,750
Sedgwick	Sedgwick	$1,418,532	$1,754,408	$1,711,319	$1,713,139
Sunflower	Barton	$137,637	$165,000	$165,000	$157,595
	Pawnee	$25,761	$26,000	$26,000	$26,000
	Rice	$44,000	$44,850	$45,700	$45,700
	Rush	$6,760	$7,030	$8,000	$8,000
	Stafford	$56,000	$56,000	$57,000	$57,000
TARC	Shawnee	$684,940	$684,940	$753,434	$791,106
TECH	Reno	$321,907	$321,907	$360,000	$340,000
Flinthills	Butler	$128,700	$133,347	$148,700	$148,700
	Elk	$20,116	$18,075	$18,000	$18,000
	Greenwood	$42,954	$39,765	$42,954	$43,000
Tri-Ko	Anderson	$31,500	$27,267	$31,500	$31,500
	Linn	$29,350	$30,000	$40,000	$45,155
	Miami	$46,235	$70,000	$85,745	$85,745
Tri-Valley	Allen	$42,664	$44,797	$45,000	$45,000
	Bourbon	$42,602	$42,602	$42,602	$42,602
	Neosho	$38,329	$40,246	$42,258	$42,258
	Woodson	$17,736	$18,623	$18,623	$18,623
Twin-Valley	Marshall	$54,720	$54,720	$54,720	$52,000
	Washington	$48,640	$48,640	$48,640	$43,023
Wyandotte	Wyandotte	$231,000	$238,000	$250,000	$250,000
No CMRC	Doniphan	$26,003	$26,003	$29,000	$29,003
	Jackson	$26,750	$26,750	$26,750	$26,750
		$9,269,492	$9,910,954	$10,196,711	$10,992,529
Statewide - 2 mills *					$29,740,172
No Facility	Chase	$0	$0	$0	
	Chautauqua	$0	$0	$0	
	Morris	$0	$0	$0	
	Wabaunsee	$0	$0	$0	
	Wilson	$0	$0	$0	

* Estimated amount which would be generated at 2 mills statewide.
Date of Report: February 11, 1994

Attachment II

MENTAL RETARDATION SERVICE AGENCIES

PERSONS CURRENTLY SERVED

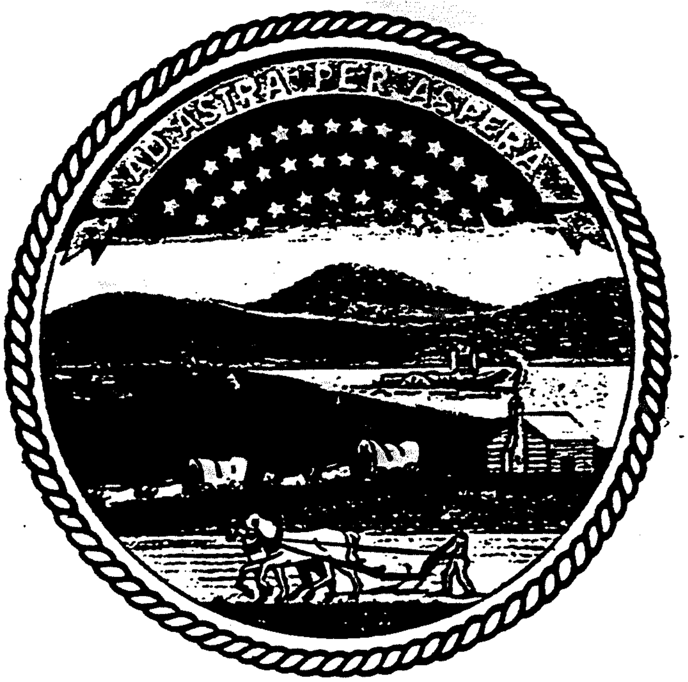
JANUARY 1, 1994

Community Mental Retardation Service Agencies have reported to SRS/MH&RS information regarding individuals who are currently being served by their agencies. The information which has been received is summarized below:

ADULT SERVICES	TOTAL SERVED
State MR Facilities	841
Private ICF/MR	961
Day Program Only	1650
Residential Only	291
Day & Residential	2171
Support	437
Adult Subtotal	6351
CHILDREN	
Early Intervention	451
Family Support	618
Family Subsidy	416
Children Subtotal	1485
TOTAL	7836

Attachment III

MENTAL HEALTH & RETARDATION SERVICES: DIVISION OF MR/DD 1993 ANNUAL REPORT



KANSAS DEPARTMENT OF SOCIAL AND REHABILITATION SERVICES

SRS Mission Statement

"The Kansas Department of Social and Rehabilitation Services empowers individuals and families to achieve and sustain independence and to participate in the rights, responsibilities and benefits of full citizenship by creating conditions and opportunities for change, by advocating for human dignity and worth, and by providing care, safety and support in collaboration with others."

July 1, 1993

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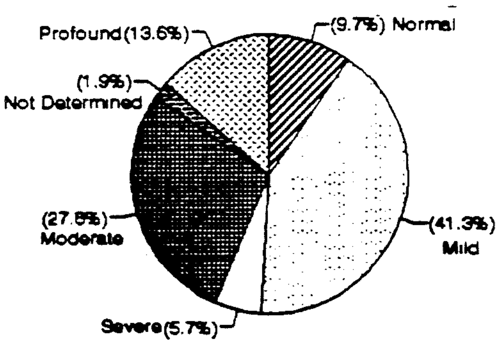
WHO RECEIVES SERVICES?

The Developmental Disabilities Profile (DDP) is used to collect information about people receiving MR/DD services and people applying for services. Currently, everyone served in state MR facilities, ICFs/MR, or with HCBS/MR money must have a DDP completed. A sample of people served in community settings with funds other than HCBS/MR has also been screened with the DDP. The information reported for people in community MR settings includes those funded with HCBS/MR as well as the sample.

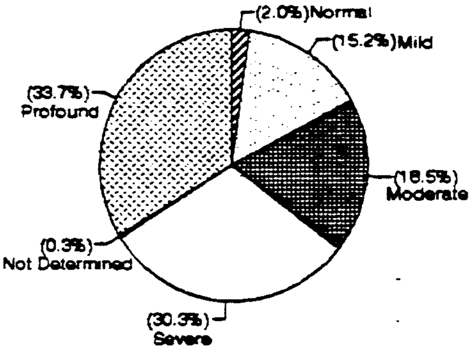
As the graphs below demonstrate, state MR facilities do not have a monopoly in providing services to persons with severe and profound mental retardation, although a large percentage of their population falls into these two categories.

Distribution of Intellectual Functioning

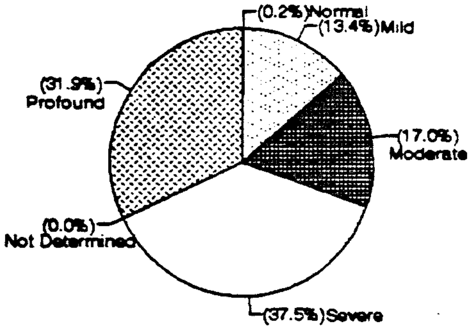
Community Settings



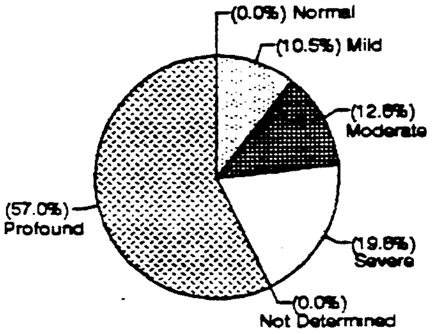
Small ICFs/MR



Large ICFs/MR

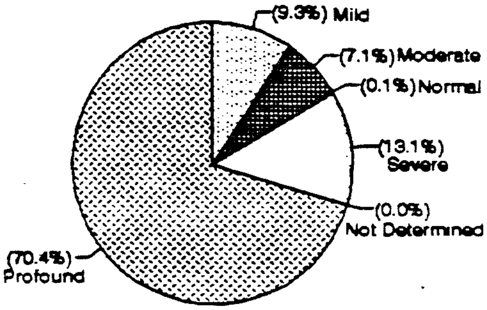


Recent Placements to the Community*

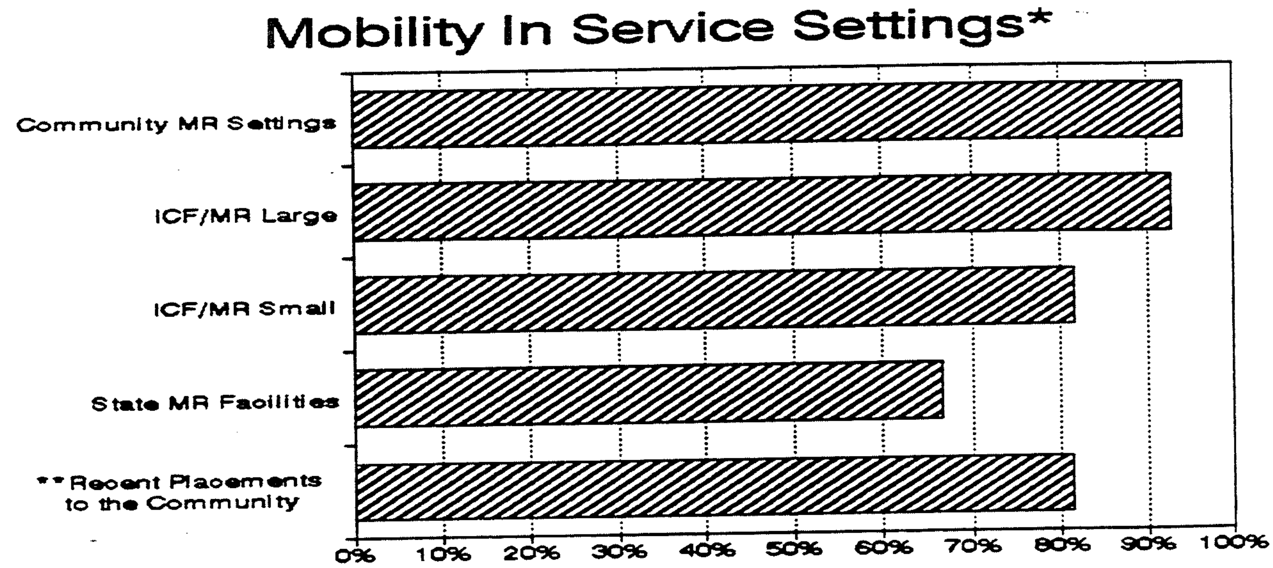


**People placed from state MR facilities since February 1992*

State MR Facilities

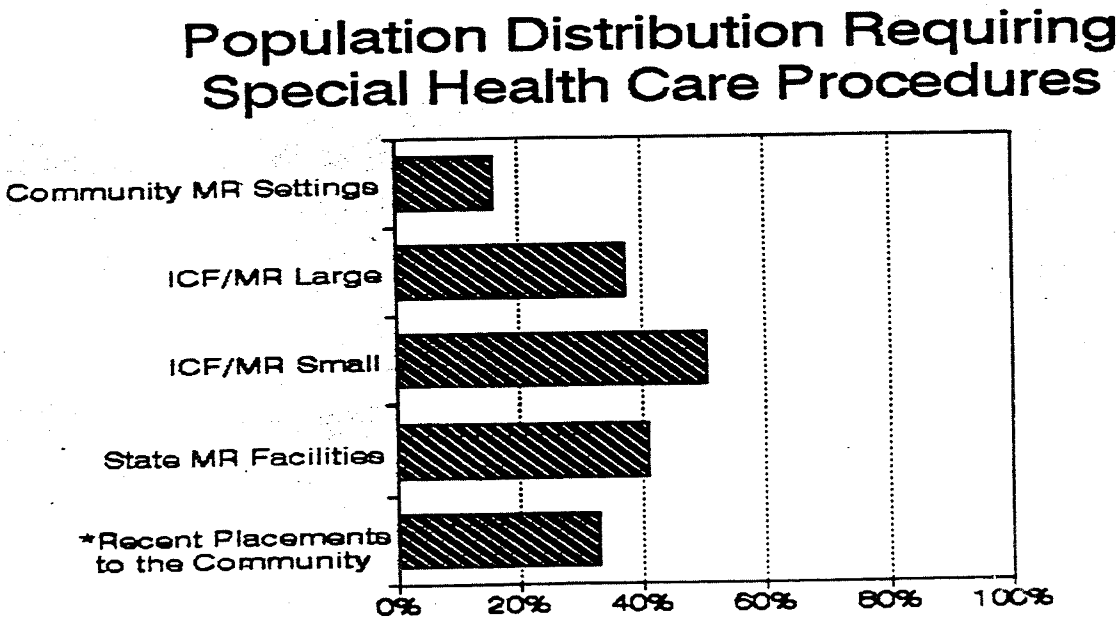


Although more people who use wheelchairs reside in state MR facilities, many of these people have some mobility. The percentage of those who have no mobility (28%) is significantly smaller than the percentage of those who use a wheelchair (43%).



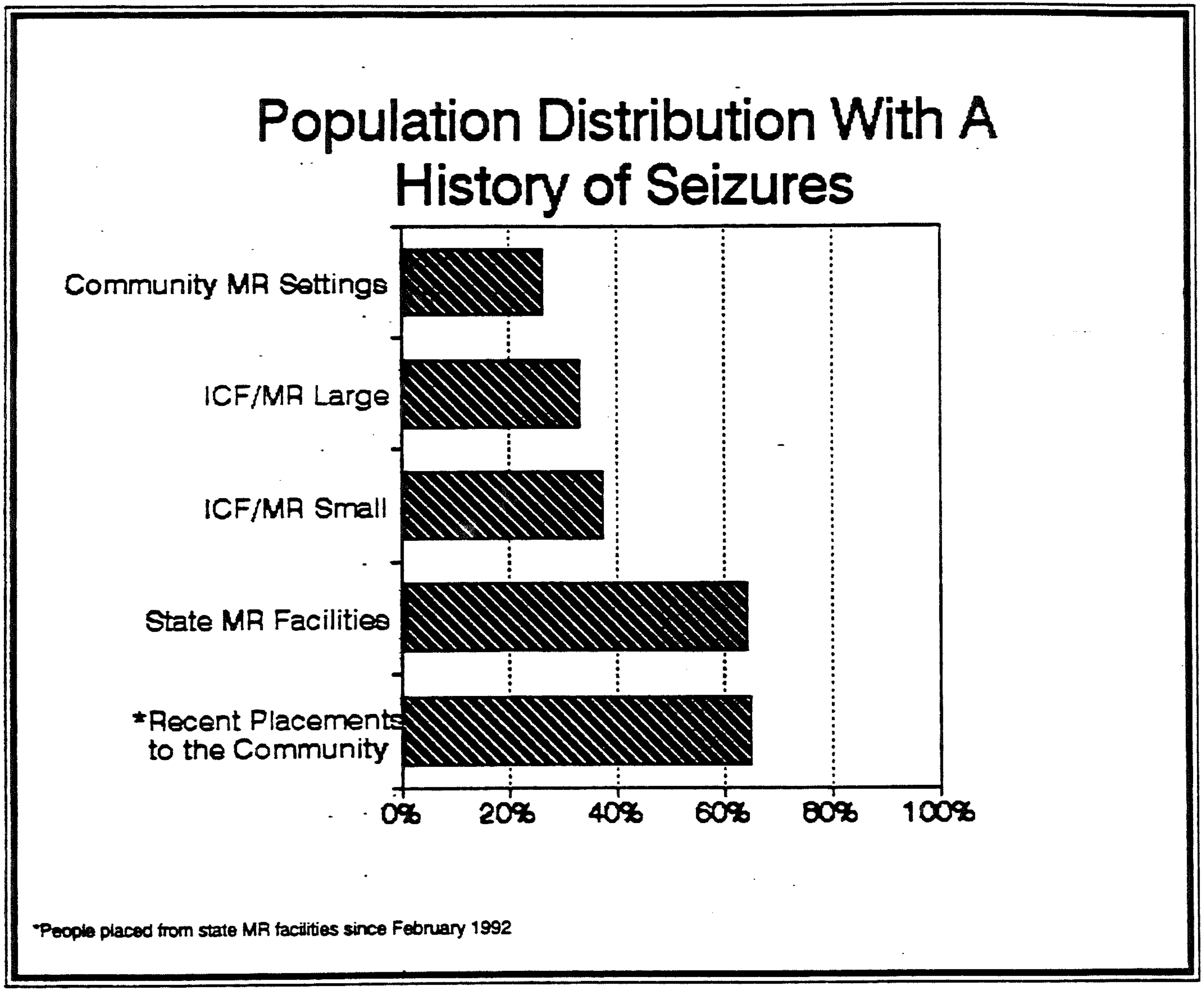
*Can walk independently, with assistance, with corrective device, or are in a wheelchair but can transfer independently.
**People placed from state MR facilities since February 1992.

Other characteristics which may in the past have made living in the community difficult include the presence of multiple medical conditions and the need for staff to be trained in special health care procedures. Such procedures range from learning the proper way to use an adaptive eating utensil to suctioning and administering tube feedings. As can be seen in the graph below, the need for staff to be trained in special procedures has not been an obstacle in recent placements from state MR facilities to the community.



*People placed from state MR facilities since February 1992

The graph below indicates that a history of seizures is not the barrier to community inclusion it once was. Person centered planning, HCBS/MR and start-up funding, and ongoing education of communities about disabilities have all played a role in making it possible to include people with severe and multiple disabilities in their communities.

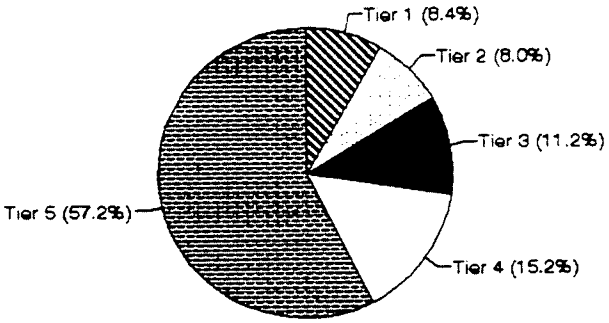


*People placed from state MR facilities since February 1992

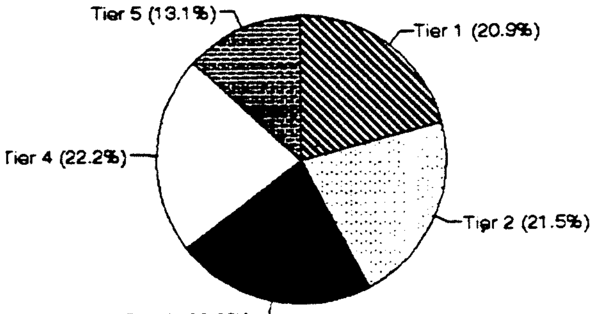
In November, 1992, MR/DD Services implemented a system of tiered rates to pay for certain HCBS/MR services. The tiers were based upon DDP scores with the greatest level of disability in a given area (adaptive skills, maladaptive behavior, or health) corresponding to Tier 1. The community is clearly able to serve persons in Tier 1 and Tier 2 as evidenced by the distribution of tiers among people recently placed from state MR facilities in the community.

Distribution of DDP Tiers by Service

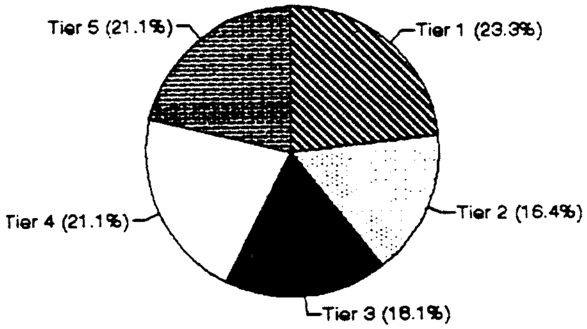
Community Settings



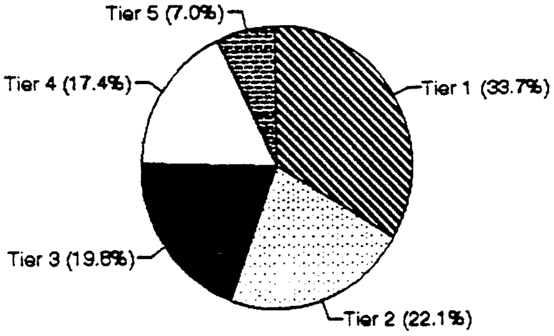
Small ICFs/MR



Large ICFs/MR

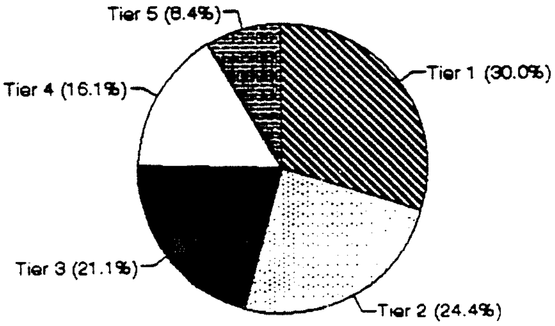


Recent Placements in the Community*



*People placed from state MR facilities since February 1992

State MR Facilities



The data clearly indicate the State MR Facilities populations contain the highest percentage of difficult to serve clients (tier 1 & tier 2) followed by the large and small ICFs/MR when comparing service settings. However, in terms of actual numbers, Community Settings serve as many tier one and tier two individuals as do the State MR Facilities, but the percentage of population is lower due to the greater number of persons served in community settings. Overall, Community Settings, Large ICFs/MR, and the Community Waiting List contain the highest percentage of tier five individuals.

Of special interest is the data that shows Recent Placements to the Community - those placed since February 1992 - are a mirror image of the distribution of tiers in the State MR Facilities. This finding indicates Community Settings have not been accepting only the easiest to serve persons as individuals have been transferred nearer their home, and reinforces the position these placements have occurred based on choices exercised by families and guardians.

All tiers are represented across all service categories. This finding supports the previous findings which showed the selected demographics and characteristics were represented across all service categories.

SUMMARY AND CONCLUSIONS

At the direction of the Legislature, this analysis was conducted to develop criteria which could be used to reliably differentiate between persons who might be appropriately served in community settings, persons who might be appropriately served in state MR/DD institutions, and persons who might be appropriately served in private ICFs/MR. The objective of the analysis was to isolate demographic and individual characteristics which would validly correlate with various service categories.

The findings indicate various degrees of variability between service categories when the data are compared on a proportional (percentage) basis. However, there is no apparent significant

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AN ANALYSIS OF PROFILES OF INDIVIDUAL CHARACTERISTICS OF PERSONS WITH DEVELOPMENTAL DISABILITIES

A Report To The Legislature
Directed By House Bill 2047

July 7, 1993

Kansas Department of Social and Rehabilitation Services
Donna L. Whiteman, Secretary

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variable, among those selected for review, which correlates with a specific type of service setting to the degree it could serve as criteria for designating appropriate service settings. All variables studied were present in significant - when compared in actual rather than percentage - numbers across all categories studied. The conclusion must be reached, based on current experience in Kansas, there are no individual characteristics which can be used to accurately determine in what service setting an individual should be placed.

This analysis did reveal significant information when comparing the categories of Recent Placements to the Community and State MR Facilities which deserves further discussion. That comparison indicates, since February 1992, there is no significant difference between institutional populations and persons transferred to community programs. This outcome was achieved by the Community Integration Demonstration (CID) project, a new methodology which was implemented to improve the process for moving individuals from the State MR Facilities into community programs.

Historically, State MR Facilities reported 20 to 50 percent of people transferred to community settings returned. The new process involves establishing a four-way partnership consisting of families, community agencies, State MR Facilities, and MH&RS. The purpose is to move individuals living in state MR hospitals into community integrated services of their choice - bypassing the traditional continuum of care based on severity of disability - by providing the individuals with appropriate supports and services thus preventing returns. The commitment is to move those individuals whose parents or guardians wanted them to live closer to home, regardless of severity of disability.

To date, over ninety-six percent (96%) of those persons placed through the CID project remain in their new home community. Preliminary data indicate the cost of serving the persons placed through the CID project is 45.3 % less than the average State MR Facility cost. The CID project was evaluated by an independent consultant who termed the Kansas Community Integration

Project "overall, ... a clear and exciting success" in a report issued in February 1993.(2) The report documents the commitment made through the CID project was successful to a degree never before achieved for a group of individuals exhibiting the same distribution of demographics and characteristics as State MR Facilities. This report is available through MH&RS.

In conclusion, this analysis and the success of the CID does not support the premise clients with certain characteristics must be served in specifically designed settings. They do suggest adoption of the principle of consumer and parent/guardian choice can be supported in any setting in the Kansas MR/DD service system.