Approved: March 28, 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 15, 1995 in Room 522-S of the Capitol.

All members were present except: Rep. Joann Flower, Excused
Rep. Sabrina Standifer, Excused

Committee staff present: Patricia Pierron, Legislative Research Department
Emalene Correll, Legislative Research Department
Marian F. Holeman, Committee Secretary

Conferees appearing before the committee: William Brotton, Starkey, Inc., Wichita
Jim Germer, Dir., KS. Advocacy & Protective Serv.
Gina McDonald, KS. Assn. of Indep. Living Ctrs.
Shannon Jones, Exec. Dir. SILCK
Carol Doss, Topeka ILRC
Brian Atwell, Director LINK
Ann Branden, Independence Inc., Lawrence
Shari Coatney, SEKS Independent Living
Robert L. Clark, Pres./CEO CLASS Ltd., Columbus

Others attending: See attached list

Hearings continued on **HB-2458.** All conferees basically support the bill. Questions and comments were discussed, and balloons with suggested language changes were welcomed from all conferees. Conferees appeared in the following order:

Bill Brotton, CEO, Starkey, Inc., a community base organization in Wichita, (Attachment 1).

Jim Germer, Director of Protection and Advocacy at Kansas Advocacy and Protective Services, Inc. based in Manhattan, (Attachment 2).

Gina McDonald, Kansas Association of Independent Living Centers, introduced conferees who are directors of centers for independent living. This group approached the bill from the perspective of looking toward the future and look forward to working on this bill and its future evolution. They were not present to attack the bill. They are pleased with the direction it is going. Ms. McDonald will provide additional testimony next Monday.

Shannon Jones, Executive Director, Statewide Independent Living Council of Kansas (Attachment 3). Centers for independent living provide information and referrals, independent living skills training, peer counseling, and individual and systems advocacy. How information regarding choice is to be dispersed is an important issue that needs to be dealt with.

Carol Doss, Topeka Independent Living Resource Center, (Attachment 4). Reiterated the need for compliance with Americans with Disabilities Act.

Brian Atwell, LINK, Inc., Hays, KS. (Attachment 5)

Ann Branden, Independence, Inc., Lawrence, KS (Attachment 6).

Shari Coatney, SEKS Independent Living Centers, spoke in support of choice for consumers and the right of independent living centers to provide options for consumers in additions to the CMRC's. No written testimony.

Robert L. Clark, President/CEO, CLASS LTD, Columbus, KS (Attachment 7). Discussion followed regarding Section 6 of the bill as it is currently written.

Minutes of the January 18 and 23 meetings were approved.

The next meeting will be February 20 at 3:30 in Room 522-S.

The meeting adjourned at 5:10 p.m.

HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES COMMITTEE GUEST LIST

DATE: February 15, 1995

NAME	REPRESENTING
Wayne Stringer	Winfield Hospital Parents Group
ED SZCZEPANIK	WINFIELD HOSPITAL PARENTS GROUP
Sharon K. Bird	Winfield Hospital - Parent Group
David Powell	Rucker, Powell & Assoc.
Lynn RUCKER	RUCKER POWELL, Ltd
Mark D. Elmore	Jo. Co. M.R. Center
Robert L. Clark	CLASS LTD
Bill Brotton	Starkey Inc.
Jim [illegible]	KAPS
Carol Doss	Topeka Independent Living Resource Center
Lisa McDonald	KACIL
Ann Branden	Independence Inc. LAWRENCE ILC
Shaun Coarney	SEKIL South East Kansas Independent Living
Shannon Jones	SILCK
Brian M. Atwell	LINK Hays
[illegible]	The Arc of KANSAS
Brenda Hanna	TILRC
Sharon Spratt	Cottonwood, Inc.
Kerry Rustick	Independent Connection, Salina

HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES COMMITTEE GUEST LIST

DATE: Feb. 15, 1995

NAME	REPRESENTING
Jan Mendell	Independent Connection/Jackson
Oruka Aldrich	RCIL
Jane Rhys	Ks Council on Dev Dis
Tim Steininger	KCDD Accessing Southwest Kansas, INC, KCDC ASK, INC & C. Consumer
Josie Torrez	Families Together, Inc.

STARKEY
INC.

Thank you Representative Pottorff and members of the committee for this hearing, and for your sincere interest in the rights and needs of persons with disabilities.

I am Bill Brotton, chief executive officer of Starkey Inc., a Wichita area organization which is in its 65th year of working with people with disabilities.

I am here today to support many of the provisions of HB 2458 because I sincerely believe in two basic principles.

First, that people with disabilities ought to have the opportunity to live and work and enjoy their lives in the community of their choice, supported by a system of community supports and services. House Bill 2458 is truly exciting because it sets strong consumer-oriented principles in the law, by making community integration a statutory policy, by expanding the scope of service to include all who have developmental disabilities, and by establishing in the law that the consumers' choice of services shall be respected by everyone in the system.

Second, that Kansas has an excellent home-grown system of supports and services in place that is in danger of becoming both fiscally and programmatically broken without

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Developmental Disabilities
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Attachment 1

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some immediate attention, that can only be given by the Legislature. This is the area of this law on which I would like to comment.

Prior to coming to Starkey's, I directed the activities of two other community based programs -- Chanute and Wellington -- in both cases as the executive director of a community mental retardation center. In both instances, we were the only community provider in the county, and coordination was a simple matter.

I now serve in a setting where there are dozens of providers, and coordination has increasingly become very challenging for all of us in the Wichita area, as I suspect is true in each of the urban centers of the state. And it is becoming true in non-urbanized areas as well.

Coordination in our county had been an ad hoc process among service providers. We formalized that arrangement a number of years ago with the formation of CARE -- County Alliance for Rehabilitation Efforts -- which meets regularly to coordinate services and to determine, among other things, the allocation of placement opportunities for HCBS applicants.

But far greater coordination would mean a more efficient system in Sedgwick County. I am pleased to report that thanks to leadership from the county and from parents in the community, working with area providers, Sedgwick County is about to reshape that system. The county will take a greater leadership role than in the past. They have indicated a willingness to consider additional local funding support, in exchange for provider commitment to a better coordinated approach.

That's what Sedgwick County is willing to do. But with so many system controls still in the hands of SRS, many are wondering what is intended for the future from the state's point of view?

I am hopeful that this bill signals a willingness on your part to make repairs to the state system, because today the system is like a car that's only hitting on a few of the cylinders.

We can continue to drive down the same road, but not efficiently. For some providers, especially smaller providers with small amounts of private donor support, or who work in counties with low property valuations, the current partnership with the state puts their financial solvency at risk.

There was a time when community providers were small and when the state was a benevolent parent, with a handful of dollars to parcel out to those who demonstrated they were doing good work. Much was done on a handshake and was based on trust.

Things can never be that simple again, because there are simply so many more people wanting service, so many more dollars in the system, so much competition for the dollars and a greater public demand for accountability and for outcome based budgets.

House Bill 2458 would set into law many system changes that at the least could provide the hope that the state and community partnership has a future. And that is at the heart of my support for this bill. The choice is between a system where local citizens and the state are in partnership, or a system where the state staffs and operates all community services.

If you want a partnership future where local citizens are empowered to plan and execute local ideas to meet local needs, then pass this bill. If you want the state system to gradually take over current community providers, then leave the current laws and practices in place.

All community based programs are prepared to embrace the new rules of modern system management. But there are no longer any rules by which we can plan our course, and set a plan in motion with any expectation that the rules will be the same tomorrow.

In effect, today there is only the very sketchy framework of the current CMRC laws, which only address about 5% of our day-to-day decision making... and the rest of the decisions are based on rules which are not always in writing and often confusing.

In light of that situation, careful review of section 6, regarding the Secretary's authority to discipline providers of service. First of all the language gives the Secretary authority to discipline only CDDO's, and I assume that is an unintentional error. The Secretary must have similar authority over all who receive and expend tax dollars for these services.

But more importantly, this appears to give overly broad powers to the Secretary over private not-for-profit corporations. I do not think that is what you want to do. The power to enforce contract language and to withdraw state funding would accomplish similarly strong results.

If you intend to seize private assets and remove board members who may have been appointed by county commissioners, or who may have as officers assumed corporate responsibilities, I fear your disciplinary proposal in this bill is not enforceable without tremendous court costs and long time delays. I think that swift remedies would be better for consumers and others involved than long, drawn out and expensive remedies.

I want to support several key elements of this bill which I believe must be preserved if you choose to move ahead with HB 2458 with the intent of establishing a strong partnership with community providers:

Maintain the concept a single point of access and referral, the so-called "gatekeeping" approach. I do not work for a CMRC, but I believe that strong CDDO's as defined in this bill, are necessary for efficient service delivery.

Maintain the requirement that all those who wish to access state funding to provide services must affiliate at the local CDDO, and have the right in exchange that their services be made known to any consumer who seeks service or assistance. All providers must work together, and it must be a two-way street.

Maintain the language that calls for "fair and reasonable reimbursement" as recommended by some independent entity, either a funding commission or by an independent firm. You need to know, before you make your appropriations decisions, whether the dollars you allocate to service providers can do the job, and deserve to know when rate requests are excessive.

This legislature has discussed the need for reform for a number of years, and I appreciate that all of you are considering these system changes. But, I am here to tell you that the time is now, not next year or two years from now.

You have heard or will hear from providers who have established agreements with the state on a variety of program decisions, and have then secured loans or raised private funding to meet those program decisions -- only to be told later when state philosophy changes that funding rules have changed as well. Programs once favored and funded by the state are no longer funded. And community boards and volunteers and staff are left holding the bag.

We favor the new inclusionary philosophy for services for people with disabilities, but at the same time, we want our partnership with the state to include rules as to how do you finance the transition from one philosophy to the next.

This bill will not solve all such problems, but by acknowledging in the law that the system is a partnership, we can solve many of our problems.

K[illegible]sas Advocacy & Protective Services, Inc.

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TO: The House Select Committee on Developmental Disabilities
Representative JoAnn Pottorf, Chair

FROM: Kansas Advocacy and Protective Services
Staff Report

RE: House Bill 2458

DATE: February 15, 1995

Good afternoon, Chairperson Pottorf and members of the committee. My name is Jim Germer, and I am the Director of Protection and Advocacy at Kansas Advocacy and Protective Services, Inc., based out of Manhattan. We are a private, non-profit corporation that assists persons with disabilities in gaining access to the rights and services to which they are entitled. We fulfill the protection and advocacy requirements of the Developmental Disabilities Assistance and Bill of Rights Act, the Protection and Advocacy for Individuals with Mental Illness Act, and the Protection and Advocacy of Individual Rights Act.

For purposes of background, we have attached a copy of our testimony on MR/DD services previously submitted to the interim Special Committee on Ways and Means Committee chaired by Representative Rochelle Chronister back in October. I will not go over it at this time.

We generally like House Bill 2458, and believe that it is a step in the right direction. We do, however, have some questions and comments, and would like to present them to you for your consideration.

First, we are very pleased with the language of Section 1 in that it tracks the philosophy of community inclusion, independence, respect for the individual, and the fact that persons with disabilities are people who have the same basic needs and wishes as other people. In section 2(c) defining "community services" *[page 1, lines 30-32]*, we would like to emphasize the inclusion of leisure and recreation as a part of community living.

We like the definitions of "Developmental Disability" and "Mental Retardation" as set forth in the bill *[on page 2, lines 5-19, 25-31]*, but as was noted on Monday, there are some differences between those definitions and the definitions currently used. We do believe that it is preferable not to tie funding eligibility for MR services to an IQ score for a variety of reasons, including the inherent measure of error in IQ testing, as well as the fact that over-reliance on IQ scores tends to preclude taking a look at the person as a person and individually assessing the need for services. The definition of "mental retardation" in the bill seems to take the more modern approach of de-emphasizing the importance of IQ scores and emphasizing adaptive need.

House Select Committee
on Developmental
Disabilities
2-15-95
Attachment 2

KAPS has been charged with developing systems of advocacy and protective
services in Kansas relevant to the provisions of Sec. 113 of P.L. 94-103, as amended; the Developmental
Disabilities Services and Facilities Construction Act, and P.L. 99-319, the
Protection and Advocacy for Mentally Ill Individuals Act.

As explained in our testimony in October (which is attached), with respect to Section 3(f) *[page 3, lines 39-42]*, we believe that the provision of quality enhancement for community living by use of DD Regional Coordinators has been a very positive step, and we commend the inclusion of language pertaining to quality enhancement.

Regarding Section 5(a) *[page 4, lines 6-34]*, questions arise regarding who will make up the community services funding commission and how it will be operated; but we do commend the emphasis on looking at employee compensation and benefits, training, technical support, and quality assurance.

With regard to Section 5(b)(2)*[page 4, lines 38-41]*, we agree that using accreditation standards is appropriate, but would caution about using national accreditation standards to supplant, instead of supplement, quality assurance and independent oversight. The people we serve need and deserve them both. There is more than one national standard, and the standard or standards used should first be approved or deemed appropriate by an outside entity, which could perhaps be SRS.

Regarding Section 5(b)(5)*[page 5, lines 13-15]*, we would caution that it not be construed to mean that community developmental disability organizations cannot extensively use "generic" community supports whenever feasible.

We very much appreciate the language in Section 6 *[page 5, lines 16-28]* regarding enforcement power, although the language needs to be reworked a little, and we would like to see clarification that any of the remedies listed could be used as needed and not necessarily have to be used in the order presented.

I am not sure that I completely understand Section 7 *[page 5, lines 29-33]*, or how it is intended to function. For example, if a community developmental disability organization is refusing to provide appropriate supports and services, SRS needs to be able to take action, and I am concerned that Section 7 could possibly be used to impede that action, although I believe that this is not the intent. Perhaps specific language could be inserted to the effect that nothing in that section is to be construed as limiting in any way the right of SRS to take appropriate action in terms of licensing, enforcement, or quality enhancement for the benefits of consumers.

A couple of main points should be made. If there is to be a gatekeeper, there must also be a mechanism for empowering consumers and family members by allowing them a way to contest gatekeeping and programmatic decisions that affect them adversely. One approach to scrutinize may be to take a look at whether something like the Kansas Administrative Procedures Act appeals process could be useful. Secondly, it may be worthwhile to specifically state the authority of SRS to formulate regulations to implement the Act. Finally, whether through this bill or otherwise, an important consideration is to assure that CMRCs and affiliates are mandated reporters of abuse, neglect, and exploitation by specifically including them in the relevant reporting statutes.

Thank you very much for your time and attention.

Respectfully Submitted,

Joan Strickler
Executive Director

James L. Germer
Director of Protection and Advocacy

Kansas Advocacy & Protective Services, Inc.

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TO: The Special Committee on Ways and Means
Representative Rochelle Chronister, Chair.

FROM: Kansas Advocacy and Protective Services
Staff Report

RE: Mental Retardation/Developmental Disabilities Services

DATE: October 4, 1994

Kansas Advocacy and Protective Services (KAPS) assists children and adults with disabilities in gaining access to the rights and services to which they are entitled. We fulfill the protection and advocacy requirements of the Developmental Disabilities Assistance and Bill of Rights Act, the Protection and Advocacy for Individuals with Mental Illness Act, the Protection and Advocacy of Individual Rights Act and the Kansas Guardianship Program. KAPS is a private, nonprofit corporation created specifically to serve these roles in Kansas. We have been in existence since 1977.

Kansas is moving from an institutionally-based, centralized, state operated service system to one that is community-based, decentralized and operated by private providers. We feel that it is important to look closely at this shift and what it may mean in terms of developing procedures and mechanisms to provide a reasonable level of protection for people in a variety (and sometimes widely dispersed array) of community settings, while at the same time empowering them to be able to make fully informed decisions and to take appropriate risks.

It must be emphasized that an individualized, community living opportunity where there is a reasonable level of freedom is preferable for all of us, including those of us with significant mental, emotional and physical impairments. Communitization has risks, however, and these need to be addressed through well-planned systems and procedures to protect the rights of and provide reasonable levels of safety for those who may be vulnerable to persons who would exploit or abuse them.

We bring the following thoughts and recommendations to the Committee's attention for consideration.

KAPS has been charged with developing systems of advocacy and protective
services in Kansas relevant to the provisions of Sec. 113 of P.L. 94-103, as amended; the Developmental
Disabilities Services and Facilities Construction Act, and P.L. 99-319, the
Protection and Advocacy for Mentally Ill Individuals Act.

Review of client rights, quality assurance, and licensing requirements for CMRCs

Historically, the development and enforcement of clients' rights policies and quality assurance programs has been left largely in the hands of the Community Mental Retardation Centers (CMRCs). In more recent times we have had the opportunity to work with the DD Regional Coordinators (or "quality enhancement" coordinators) for community mental retardation/developmental disabilities providers and we have generally been quite favorably impressed. It is very important for agencies to maintain internal control mechanisms, but when we are dealing with client rights and quality assurance, there is always a need for independent oversight. The new "hands on" variety of effort shown by Developmental Disability (DD) Regional Coordinators (or Quality Enhancement Coordinators) is a good start and deserves support.

A critical concern is ensuring that clients can adequately assert their rights by making sure that a mechanism exists for them to contest decisions made by service providers that adversely affect them. This should include recourse to an independent decision maker, especially in dealing with areas that significantly impact people's lives.

Licensing of community based service providers is also a central consideration. The present State licensing requirements need to be changed and updated. However, in so doing, balancing appropriate protections and risks needs to be a constant consideration. On the one hand, we cannot have burdensome, bureaucratic laws and regulations that suppress innovation and hinder consumer growth. On the other hand, we also cannot have inadequate laws and regulations that have no "teeth"; that is, that leave the State and/or other oversight entities without the ability to swiftly react to, deal with, and if necessary, shut down providers that are not adequately addressing issues of client rights, health and safety.

Mandatory ANE Reporting

Abuse, neglect and exploitation (ANE) can occur in a wide variety of settings and programs. Through our work with the protection and advocacy programs, and through the guardianship program, we deal with people experiencing problems involving physical abuse, which may or may not involve sexual abuse and exploitation; problems of financial exploitation; and problems stemming from neglect. Such incidents may occur in large facilities or in a variety of community settings. They may involve physical abuse of a consumer by a facility staff person, exploitation or abuse of one consumer by another, or financial exploitation by family or so called "friends" who appear miraculously when a Social Security check arrives. Problems can also stem from neglect by service providers, by family, or by the person's inability to care for the person's self.

Currently, while certain personnel because of their professional status must report abuse, neglect, exploitation; community mental retardation/developmental disabilities centers are not listed by law as mandated reporters. We believe they should be included.

We recommend that KSA 39-1402 and KSA 39-1431 be amended to require that mandatory reporting under the abuse/neglect/exploitation statutes include, at least, case managers and chief administrators of Community Mental Health Centers (CMHCs) and CMRCs as mandated reporters. We understand this is accomplished by contract agreements with MH/RS but believe such requirements should be in statute.

We also recommend that the State maintain a central reporting registry with regard to ANE. This would assist in the identification of general problem areas and would help identify specific persons in the field who have a history of abusing or neglecting clients and keep moving from facility to facility, repeating acts of abuse or neglect. We further recommend that the State maintain a central reporting system of all deaths of persons in State hospitals and of persons receiving community services provided through contract with private providers.

Review of the role of adult protective services

The deinstitutionalization effort has had and will continue to have a growing impact on the demands placed upon adult protective service workers. We are involved on an ongoing basis with SRS adult protective service staff. We have a great deal of respect for these individuals and for what they must do.

As with the community service system generally, we find many areas of the State well served by experienced, capable social workers. There is, however, sometimes a lack of consistency in the type, quantity and quality of services that are delivered throughout Kansas.

We recommend that adult protective services be recognized as a key element in the risk management system for a community services system. We suggest that an assessment be made of the responsibilities of adult protective services and the training and support needs workers will require to be key partners in assuring adequate protections for people with mental and other disabilities who live in community settings.

It is essential that SRS - Adult Protective Services have the ability to perform competent, independent investigations. The following excerpt from an article in the Tuesday, March 29, 1994 *Philadelphia Inquirer* illustrates what can happen without independent oversight [the article discusses a recent opinion from U.S. District Judge Raymond W. Broderick dealing with some of the class members of the famous *Pennhurst* deinstitutionalization case]:

> "'Class members are frequently abused and neglected,' he [the judge] wrote. The city and state have failed to protect the former Pennhurst residents by allowing private contractors to investigate incidents of abuse and neglect in group homes that they operate. This, the judge wrote, 'is akin to putting the fox in charge of the hen house.'"

Mandatory reporting and competent, independent investigation of alleged abuse and neglect helps everyone. It helps the State by shielding it against criticism that it is not providing protection to vulnerable people. It helps private service providers by protecting them against allegations of conflict of interest (e.g., of the "fox guarding the chicken house" variety) when they investigate possible wrongdoing of their own employees or when the situation might cause possible embarrassment for them in the community. Obviously, however, it helps persons with disabilities who are receiving services the most.

MR/DD Reform

The State's role in the MR/DD system is all too often viewed only in terms of maintaining, downsizing or closing one or more large institutions. This is, of course, a critical issue, but the role must be seen in broader terms.

The community-based system, as it exists, is a private provider system. What responsibility does the State have in terms of assuring an acceptable level of accountability from those service providers? We all want a basic assurance of quality in the types of services provided and in responsiveness to consumer needs and preferences. Certainly we expect some oversight in protection from harm issues involving suspected abuse, neglect and exploitation. We expect fiscal accountability.

Beyond that, certain questions arise. Should the State maintain a role as a service provider? If so, for whom? Would this be for persons who are a serious danger to self or others? Would it include persons for whom appropriate services might not yet be available in the community? What does the concept of consumer/family choice mean in institutional vs. community placements? If the State has a continuing role as a provider, is it only in maintaining large bed institutions or is it as a part of the community provider system? We raise these questions simply because they should be considered and addressed.

We all want people to be able to move out of state mental retardation hospitals/training centers into less restrictive settings. However, elimination of the services and responsibilities of state hospitals could have very negative effects if adequate services are not provided or if responsibilities are not borne in the community. Currently we have designated catchment areas assigned to designated CMRCs throughout the State. This gives a high level of control and authority to those providers. It also eliminates, for the most part, the element of competition in the marketplace. Choice, for consumers and their families, becomes necessarily limited in selecting providers.

If we are to take this approach to a designated provider system, the private agency becomes more of a quasi-public entity. It makes sense that the State spell out the responsibilities to which the provider will be held accountable and the population that providers must serve. We believe that if Kansas is to have a community-based system of services that will reduce the need for institutional placements and prevent people from getting lost - in or out - of the service system, CMRCs must fulfill the role of gatekeeper. With control and authority comes an equal level of responsibility.

In looking at MR/DD reform, we suggest that consideration be given to using the general approach recently taken by Kansas in Mental Health Reform. If a task force or commission is to be created to assist in studying the implications of such an approach, we believe it should include broad representation.

It would be helpful to have the perspectives of:

--Consumers and consumer groups
-- Families and Guardians of Consumers
--County Commissioners
--Legislators
--SRS - Mental Health and Retardation Services, Adult Protective Services, Vocational Rehabilitation
--Providers - CMRCs, Independent Living Centers, ICFs/MR, Nursing Homes, State hospitals
--Business
--Health Care Providers - mental and physical
--Developmental Disabilities Council
--Developmental Disabilities Protection and Advocacy Agency
--University Affiliated Program
--Advocacy agencies and groups
--General Public

Summary

We should note that the concerns we mention are not necessarily unique to Kansas. In a hearing before the Subcommittee on Regulation, Business Opportunities, and Technology of the Committee on Small Business of the House of Representatives, it was noted that

> Too often, providers are left to operate on a sort of "honor" system. State authorities believe that conditions are up to standard primarily because they have been informed that is the case by the care giving company.
>
> With respect to staff at the facilities, the subcommittee found a pattern of inadequate pay and undertraining...
>
> ...in many states a principal problem is that there is no competition, and there are too few providers...

As far as some possible remedies, the same Subcommittee noted:

> ...[i]t is critical that we have better quality assurance programs...
>
> ...States must establish minimal training requirements for facility employees...
>
> ...The subcommittee would discourage States from overreliance on any single provider and encourage them to beef up financial auditing of providers. Abusive providers, providers with a history of violations, need to be run out of business quickly.

Growth of Small, Residential Living Programs for the Mentally Retarded and Developmentally Disabled, Hearing held in Washington D.C. on March 29, 1993, 103rd Congress, First Session, Serial No. 103-8, pp.2-3.

In New York, Clarence Sundram of the NY Commission on Quality of Care for the Mentally Disabled aptly summarized some of the central issues with which we must struggle in implementing the new person-centered, community-based paradigm of service provision. We have attached a copy of his address to the Young Adult Institute Annual Conference in New York City on May 6, 1993, in its entirety. It is entitled: *Consumer Freedoms and Professional Responsibility.*

We do not wish to imply that our MR/DD service system in Kansas not a good one. We have been pleased to see the system evolve and improve over the years. There are many knowledgeable and dedicated people at the State and community level, in both public and private, who have set new directions that have enriched the lives of individuals with mental retardation and other developmental disabilities.

We are of course in the midst of a tremendous philosophical change, or "paradigm shift" in the provision of services and supports to persons with disabilities which is sweeping the nation, moving to a person centered, individualized, community based, empowerment approach. The news we receive of how people grow when they are provided with appropriate supports and services in the community is heartwarming. Targeted Case Management has been established. Quality Enhancement is underway. The Community Integration Project is systematically getting people out of state hospitals and providing them with wrap-around supports. There is greater staff training; the KUAP Direct Care Staff Training Curriculum is nationally recognized. There is more in-depth training on interpersonal relationships and abuse prevention for both staff and consumers. There is greater realization of the important role that the family plays in the lives of persons receiving MR/DD services. There are much greater funding opportunities and service options for the people we serve. Our remarks are meant not as criticism of the past, but are merely to provide perspective as to how the system can and should improve in order to better serve our fellow Kansans with disabilities.

Respectfully submitted,

Joan Strickler
Executive Director

James L. Germer
Director of Protection and Advocacy

2-8

Consumer Freedoms and Professional Responsibility

Address of Commission Chairman Clarence J. Sundram, at the Young Adult Institute Annual Conference, May 6, 1993, New York City

All over this country, we have been witnessing the accumulated effects of advocacy efforts of the past two decades. The voices of consumers and families, advocates and professionals, providers and regulators have slowly chipped away at the belief that people with disabilities are so different from the rest of us, so needy, so dependent, that they need to lead separate lives in institutions or congregate care facilities in "the community." These voices, lonely and shrill at first, persevered through many defeats and occasional victories, and gathered strength, respectability and converts to change the vision for the future.

Today, we are hearing bold new visions articulated, not just by powerless dreamers but by elected and appointed governmental officials and by key leaders in the community of professionals that serves people with disabilities. Not only are the visions changing, but so is the reality of what is occurring in the delivery of services. I want to talk about the important implications these new visions and changes have for each of *us*, in a very personal way.

The Momentum of Reform

In New York State, since the signing of the Willowbrook Consent Judgment, we have been embarked upon a radical reform of the service delivery system — a reform that began haltingly at first, and moved in fits and starts, but nevertheless gathered momentum as, inexorably, the correctness of freeing people from unnecessary institutional confinement became evident. That experience has been mirrored and duplicated all across the country. In these past two decades, we have been learning, and people with mental retardation have been teaching us, how much we have in common, how much their needs are like our needs—for family and friendships, for a place to call one's own, for satisfying work, for a chance to succeed, and to fail, for a chance to reach beyond one's grasp.

Tens of thousands of children who would have been excluded from a normal life at school age now attend neighborhood schools. Fiscal policies have been changing to support a wide range of community services. For example, family support programs and supported work have grown from modest pilot programs to become significant items in state budgets. With the home and community-based waivers, most states are now focusing even more closely on the needs of the individual and on their choices and preferences. With the successes of the past, our ambitions and aspirations are continually changing and the very pace of change is accelerating.

Twenty years ago, we advocated for small ICFs in the community, for enough sheltered workshops and day treatment slots to meet the needs of people being discharged from institutions. Today, in much of the country, we are trying to get rid of the ICFs and sheltered workshops and day treatment programs and to look instead for more normalizing living and work experiences.

In this journey from where we were to where we are, there have been major changes in the respective roles and powers of government and of the individual.

A diagnosis of mental retardation and consignment to an institution was once usually sufficient to strip away not only the rights of citizenship—such as the right to vote, to contract, to obtain licenses, to manage property—but also to remove many of the attributes of personhood—the right to decide where to live and with whom, the right to marry and procreate, to make decisions about medical care, and so on.

> **We seem to be replacing the old stereotype of people who are mentally retarded as hopelessly dependent, with a new stereotype of a rugged individualist, capable of coping with a hostile and dangerous world, if only given the chance.**

The laws today have changed. Not only are people with developmental disabilities not being shipped away to institutions as they once were, but they are also not being *automatically* stripped of their competence and their rights. Instead the evolving direction of the law is to recognize the full right to citizenship of every person, despite the significant physical and mental disabilities they may have. And as the law has evolved, so have professional attitudes. We have gone from a belief in consumer participation to consumer *direction* in the decision-making process, and placed increasing emphasis on providing choices to empower people to take control of their lives.

> **Worst of all, in some instances, local regulatory staff learned of the practices but also didn't blow the whistle or take action out of fear of surfacing problems *with which the service system was unprepared to deal.***

Why am I taking up your time to tell you what most of you already know? It is because I think we have tended to be seduced by the power of these new ideas of equality, autonomy, and inclusion to the point that we have relied more upon hope and belief than upon good judgment and careful planning to help make these ideas a reality. In the process, we seem to be replacing the old stereotype of people who are mentally retarded as hopelessly dependent, with a new stereotype of a rugged individualist, capable of coping with a hostile and dangerous world, if only given the chance. Both stereotypes contain serious misconceptions and fail to confront the reality that the class of people who are mentally retarded embraces a broad range of functioning capacity and includes people with significant areas of incapacity as well.

Changing Responsibilities

I believe that in the process of implementing these profound changes in policy, we have not recognized this reality enough and have paid insufficient attention to the changing professional responsibilities that should accompany the new consumer freedoms. We have failed to squarely address the residual responsibility of people working in human service systems to safeguard people who may be endangered by their limited abilities and life experiences. And this failure to directly deal with these central issues of professional responsibility is manifesting itself daily in demonstrable harm to people with disabilities. Why do I say this?

It is because, in my role with the New York State Commission on Quality of Care for the Mentally Disabled and in the work that I have done in the service systems of several states, I have seen too many casualties of a failure to directly address the issue of professional responsibility in this age of person-centered, preference-driven service systems.

Irresponsibility Examples

Let me give you a few examples of incidents that have occurred within the past couple of years, some within the past few months:

- A profoundly mentally retarded man was placed in a private home. It soon became apparent to staff from Protective Services that he was living in a small, filthy and barren room, spending his days semi-nude, sitting on a commode. While professionals from several agencies dithered for a period of *years* about who should take responsibility, he suffered malnutrition, dehydration, decubitous ulcers and gangrene which eventually caused his death. The reason for inaction? A lack of clarity about legal responsibility for decision-making.
- Developmental disabled adults, exercising their right to procreate, are attempting to raise several children on their own. However, their limited abilities result in the children sometimes not getting sufficient food, health care or supervision. Parental frustration with their incessant needs sometimes results in abuse. Their case manager has enrolled them in parent training programs, and arranged for home aides whose intrusion they resist. The pattern of problems hasn't changed much and the children are still periodically abused and neglected. But no one seeks protective services for the children because they don't want to turn their "client" in or risk them losing their children.
- In yet another case, a 40-year-old autistic, non-verbal man lived in a community residence and attended day programs. Staff supervised him carefully because he would constantly seek food and coffee, rifling through garbage, stealing others' food and drinking scalding hot coffee when he feared discovery. Once he learned to use transportation, he was allowed more freedom. He soon became a common sight in the community— picking through garbage, begging, urinating in public places. He became an object of ridicule in the community and gained over 30 lbs. in a few short months. Professional staff took a hands-off approach, citing the "dignity of risk" in his new found freedom.
- A severely mentally retarded resident of a community program was heard screaming in his bedroom. When staff responded, they found him trapped face down between the mattress and the wall, with his underpants around his knees. He was yelling and crying and visibly angry as another resident was on top of him, pinning him down. The other resident's sweatpants were around his knees. This man has a history of sexual aggression against other residents and staff. Following staff intervention, they concluded that the incident was consensual, presumably because neither resident had been adjudicated as incompetent. Notably, staff concluded that neither resident had knowledge about sexual activity nor would they respond to sex education.
- Another severely retarded man, living in greater independence in a supported apartment, and finally free of a representative payee, spent his SSI check on crack and calls to a sex line. As a result, he didn't have money to pay his rent or to buy food for the month. The agency considered his non-payment of rent due to his poor money management skills as a choice. At first, they withheld his Personal Needs Allowance to pay back rent. But their even-

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Consumer Freedoms

Continued from page 8

In "de-regulating" services as a reaction to the regulatory overkill of the ICF/MR era, the service system has largely eliminated clear expectations that people will be reasonably protected from harm, has delegated much of the responsibility for monitoring back to the provider, and has almost insured its ignorance of any problems that develop.

tual solution? Summary eviction from his apartment by placing all his belongings in garbage bags in the hallway. Presumably this was a lesson in normalization and consequences that, whatever its pedagogic value, left him homeless and broke.

These case examples can continue, describing people with severe disabilities living in the community in independent and sometimes unregulated settings, as part of this new movement to individualize supports. In some cases, we have seen people who are said to choose:

- to forego medical attention for serious and curable health problems; or
- to engage in dangerous, antisocial and sometimes criminal behaviors that jeopardize their freedom.

One of the bedrock beliefs about community living was an end to social isolation in an institution and the availability of the safeguard to be provided by different pairs of eyes, different relationships, different circles of friends and the protection inherent in each of these connections. When agencies have taken the time to work on community integration rather than community placement alone, they have found that this process works and helps enrich the lives of both the individual being brought into the community and those around him. But it is a slow and intensive process, with large hidden costs in the time to develop and nurture these individualized connections.

When placements are made on a larger scale, especially under the pressure of court orders or budget cuts, as is more often the case, there is neither the time nor the fiscal luxury to invest in developing these highly individualized but essential connections.

Segregated In the Community

Thus, what we see in many parts of the country, where large numbers of placements have been made, is that people who once lived in segregated institutions have been *transplanted* into the community but are still living segregated lives. They live, work and recreate together. They go every morning, in the same van, to the same day treatment center or sheltered workshop, spend their day with other people like them, come home and have dinner with the same group, and stay isolated from the community until the van picks them up the next morning. On the weekend, they go bowling together and may attend a church where they have an area set aside for them. They live in the community but are not part of it in anything but the literal sense. The quality of their lives and the protection of their human rights depend almost entirely on the quality and the commitment of the staff of the particular program to which they are assigned. Many are fortunate to find themselves in programs staffed by a superb and committed staff. But others are not as lucky.

In the cases I've described, the safeguards didn't work because the people had no real connections. In some cases, professionals who knew of conditions which endangered the individuals didn't intervene for fear of hurting their working relationships with other providers. Worst of all, in some instances, local regulatory staff learned of the practices but also didn't blow the whistle or take action out of fear of surfacing problems *with which the service system was unprepared to deal.* Thus, not only did these practices go unchecked and uncorrected but, in a perverse way, *they became precedents for acceptable conduct of staff working with vulnerable people.*

In the cases I have described and the countless others I am sure you can dredge up from your own experiences, the solutions aren't always self-evident. There are often no clear rules to follow, no regulations that prescribe action. But it is precisely this void that activates the responsibility that belongs to anyone professing to be a professional—to apply a concerned judgment to the dilemmas presented in a changing world.

The safeguards that theoretically exist in community living won't work if each of us values our professional relationships with other agencies more than our commitment to the people they serve.

Shibbolets Excusing Inaction

My point in calling attention to these cases is to note that the professionals involved in them were simply not prepared to take responsibility for the tangle of issues confronting them nor to aggressively seek their resolution. Instead, they found refuge in comforting shibboleths—like the dignity of risk, the presumption of competence or the virtue of choice—that excused their inaction, while doing nothing to protect from foreseeable harm the people they ought to have been concerned about. The service system itself, while spending a great deal of time in creating new service options and extolling the value of consumer choice, had nevertheless left them alone to wrestle with a world of changing expectations. And in "de-regulating" services as a reaction to the regulatory overkill of the ICF/MR era, the service system has largely eliminated clear expectations that people will be reasonably protected from harm, has delegated much of the responsibility for monitoring back to the provider, and has almost insured its ignorance of any problems that develop.

While we need to maintain a decent respect for the right of people with disabilities to make the decisions they can, to quote Judge Friendly, we ought not to leave our common sense at the door when we go to work. People with severe cognitive limitations and limited life experience may want to make their own decisions and even believe they are making good decisions. They may unquestionably have the right, as we all do, to be dead wrong and make poor choices and mistakes, and hopefully to learn from them.

The greater the freedoms they enjoy, the greater will be the natural tension between their rights and the risks to them and to others involved in their lives, such as their children.

There are, unfortunately, no clear bright lines to demark the precise threshold at which outside intervention in their decision-making is acceptable or even obligatory for involved professionals. While laws define rights, they don't deal well with the ambiguity that is part of life. Thus, the legal process relies on the slow evolutionary method of case law to flesh out the contours of unclear legal obligations.

Onus of Making Sensitive Judgments

But, as clinical professionals who do not have the luxury of evolutionary time to make the decisions that confront you daily, the onus is on *you* to make intelligent and sensitive judgments about intervention, with compassion for the rights and aspirations of the person involved, and with an eye firmly fixed on the hazards inherent in their decisions.

I respect the difficult questions you must confront, the values you must weigh as you deal with abstract legal theories in the concrete reality of the lives of people with whom you work. The task would be somewhat more manageable if *legal ambiguity* is not compounded by *professional ambivalence*. My prayer is that we will all encounter fewer clinical professionals who act like bad lawyers and hide behind formal legal rituals and jargon—like the presumption of competence and the dignity of risk—to avoid confronting the untidy reality of human problems.

Safety Nets

The people with disabilities we all care about need guides and helpers who are concerned enough to be assertive enough to protect them from the catastrophic consequences of their own uninformed or inexperienced judgment. We have all heard a great deal about "safety nets" to protect the poor, the weak and the vulnerable. The safeguards that theoretically exist in community living won't work if each of us values our professional relationships with other agencies more than our commitment to the people they serve.

They won't work if we let a misguided sense of politeness permit on-going harm to vulnerable people.

They won't work if, in order to get along we go along with practices that expose people to unnecessary risk.

They won't work if we turn a blind eye and a deaf ear to the unspoken cries for help.

There is no safety net that can bear the weight of human indifference. And I have yet to encounter a safety net of laws, rules, regulations and policies that was any stronger or more effective than a single concerned and engaged professional, standing shoulder to shoulder with a person navigating the daily challenges of life in the community. Fortunately, there are thousands of such professionals drawn to this field whose personal values and commitment make the idea of consumer freedom more than mere rhetoric.

Almost 2,500 years ago, one of the most ancient of our professions was launched with these four words as its enduring foundation: "First, do no harm." That is still good advice for any professional, and to which I would add "and let no harm be done."

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Statewide Independent Living Council of Kansas SILCK
700 S.W. Jackson, Suite 1003, Topeka, KS 66603 ☎ (913) 234-6990 VOICE / TDD ☎ (913) 234-6651 FAX

TESTIMONY TO
SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES

Statewide Independent Living Council of Kansas
Shannon M. Jones
February 15, 1995

Good afternoon, my name is Shannon Jones and I am the Executive Director for the Statewide Independent Living Council of Kansas, (SILCK). I appreciate the opportunity to testify today on House Bill 2458. On behalf of SILCK I would like to congratulate this committee for your commitment to exploring options to better serve the MR/DD population. We agree the best way to increase independence and productivity for individuals with MR/DD is to meet their needs in the community with service options and supports appropriate to each individual.

What we have learned from this committee is that there are not a lot of options available for people with mental retardation and developmental disabilities. In fact there is only one! Community Mental Retardation Centers (CMRC) are the only entry point for the mental retardation service system. The primary issue that concerns the SILCK about H.B. 2458 is that it continues to reward the monopolistic service provider system that is currently in place. It has been our intent and hopes that this committee would recognize that Centers for Independent Living (CIL's) are also available to provide quality services to the MR/DD population. In fact the DD Reform Act of just last year specifically states that providers of services would NOT be limited to Community Mental Retardation Centers and affiliates but would also include Centers for Independent Living. *Why now, in 1995, are we taking a step backwards?*

The achievements of CIL's over the past few decades have had tremendous positive impact on the lives of individuals with significant disabilities. Again, I stress to you that CIL's are not asking to replace the CMRC's but merely to be recognized as another option for quality services to be provided . There are 12 CIL's located throughout the state compared to 48 CMRC's . We simply support expansion of service options. During these difficult economical times, it is incumbent upon us to establish a competitive and cooperative network of service providers. CIL's can assist in making the goal of serving the needs of all people a reality. Through improved coordination and collaboration among service providers and customers and with a clear mission that individuals with significant disabilities have the right to participate in the mainstream of society, continued progress will occur.

SILCK request that you include Centers for Independent Living as service providers and not limit a consumers choice to only a CMRC and it's affiliates.

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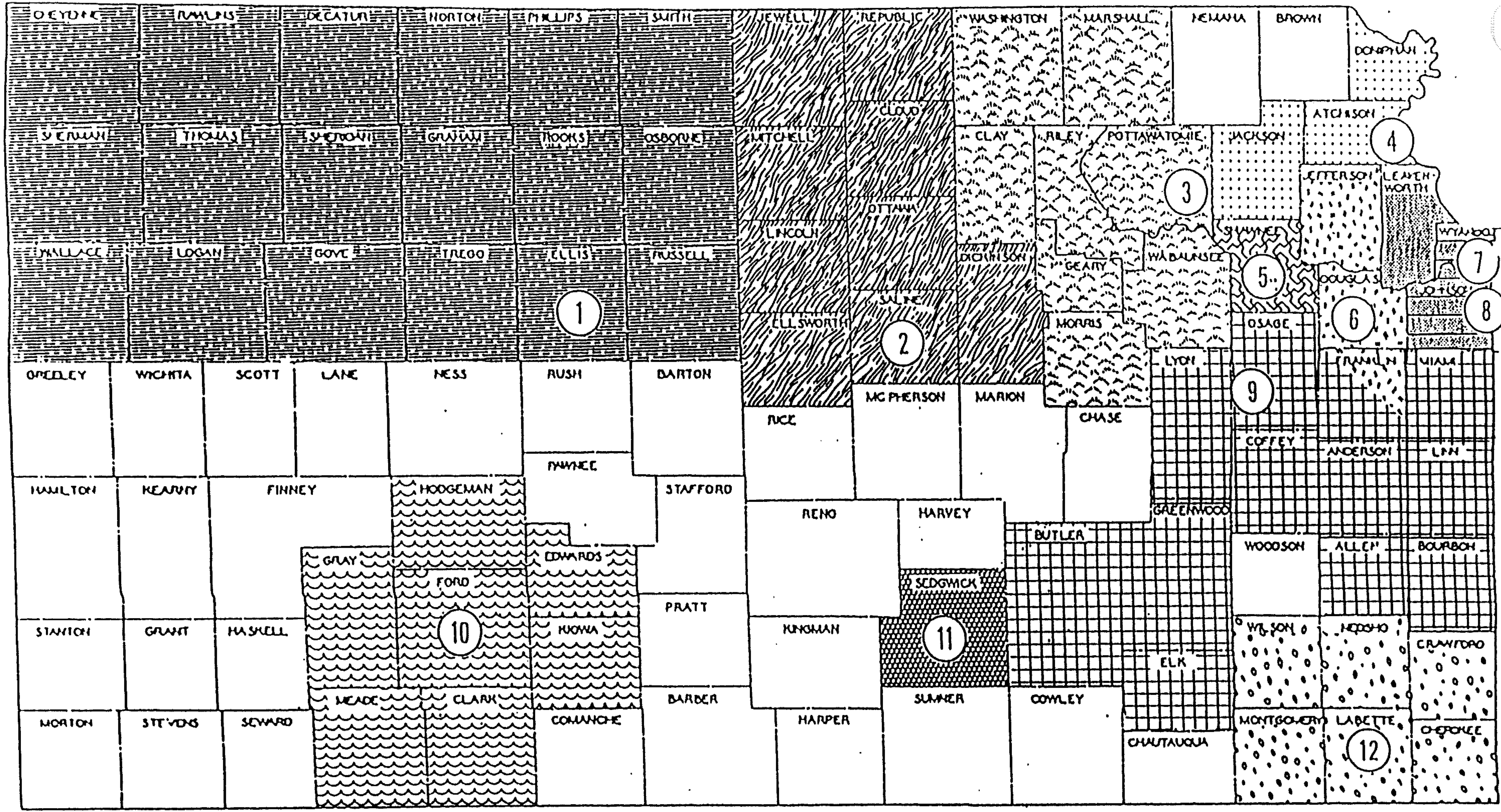
Attachment 3

3-1

3-2

Independent Living Centers in Kansas



LINK, Inc.
1310 Walnut
Hays, KS 67601
(913) 625-6942 V/TDD
(LINK also operates satellite offices in Goodland, Osborne, and Hill City.)

Independent Connection
1710 W. Schilling Rd.
Salina, KS 67401
(913) 827-9383 V/TDD

Three Rivers, Inc.
403 Lincoln Ave.
Wamego, KS 66457
(913) 456-9915 V/TDD

4. Independent Living Center of Northeast Kansas
PO Box 17, 504 Santa Fe
Atchison, KS 66002
(913) 367-1830 V/TDD

5. Topeka Independent Living Resource Center, Inc.
501 SW Jackson, Suite 100
Topeka, KS 66603
(913) 233-4572 V/TDD

6. Independence, Inc.
1910 Haskell
Lawrence, KS 66044
(913) 841-0333 V (913) 841-1046 TDD

7. Access to Living/Coalition for Independence, Inc. *(Serving Leavenworth, Wyandotte and Johnson counties)*
4631 Orville, Suite 101
Kansas City, KS 66102
(913) 287-0999 V/TDD

8. The Whole Person, Inc.
(Serving Wyandotte and Johnson counties)
3100 Main, Suite 206
Kansas City, MO 64111
(816) 561-0304 V/TDD

9. Resource Center for Independent Living
122 S. 6th, Osage City, KS 66523
(913) 528-3105 V (913) 528-3106 TDD

10. Accessing Southwest Kansas, Inc.
809 S. 14th
Dodge City, KS 67801
(316) 225-6070 V/TDD

11. Independent Living Center of Southcentral Kansas, Inc.
1900 N. Amidon, Suite 101
Wichita, KS 67203
(316) 838-3500 V/TDD

12. Southeast Kansas Independent Liv
PO Box 1035, 1817 Crawford
Parsons, KS 67357
(316) 421-5502 V (316) 421-6551 TDD

3-2

Offices located in
the Historic Crawford Building

Topeka Independent Living Resource Center

(913) 233-4572 V/TDD • Fax (913) 233-1561 • 501 SW Jackson St • Ste 100 • Topeka, KS 66603-3300

Testimony Regarding the Developmental
Disabilities Act: HB 2458
Carol J. Doss, Advocacy Manager

My name is Carol J. Doss. I work for the Topeka Independent Living Resource Center (TILRC), a services and advocacy organization for people with all types of disabilities, including developmental disabilities.

The mission of our agency is to increase consumer choice, to empower people with disabilities to run their own lives to the maximum extent feasible, and to increase the capacity of our community to integrate people with disabilities into all aspects of life including work, recreation, transportation and public accommodations.

Basically, our goal is to see that the Americans with Disabilities Act is fully implemented and the promise that this civil rights legislation holds to people with disabilities is realized. To accomplish this goal, we offer direct services and advocacy upon request, and free of charge to individuals. WE HAVE NEVER HAD A WAITING LIST for our services.

Topeka Independent Living Resource Center does not support HB 2458. We are opposed to HB 2458 for the following reasons:

1. It is not in keeping with the Americans with Disabilities Act (ADA). The ADA requires that services to people with disabilities be provided in the most integrated setting appropriate to the needs of the individual. A recent federal appeals court decision clarifies this requirement by finding that waiting lists for people to move from restrictive, institutional settings to the community setting of their choice is illegal (No. 94-1243, US Court Appeals - 3rd Cir, Idell s. v. Karen F. Snider, Jan. 31, 1995).

Nothing in 2458 addresses this important civil rights requirement of the ADA. It is less than opportune to avoid recent case law regarding the delivery of appropriate services to people with disabilities, particularly under the aegis of "reform".

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2. HB 2458 does not increase consumer choice, rather it concentrates decision making into the hands of certain agencies. These agencies are designated on the unscientific basis of historical existence. "First in time, first in right" may be an adequate basis for western water law, but it hardly holds water for determining who gets to be the gate keeper for service delivery and is certainly anti-consumer choice.

3. HB 2458 sets up monopolies. The language in the bill speaks to the right of "affiliates" to provide services. The practice, however, has been that the designated agencies have kept independent living centers such as ours from providing services and have denied people from making informed choices by not providing referrals to people so that they can explore the service options that are otherwise available. In other words, setting up a monopoly does not end "turf" issues, nor has it been conducive to getting rid of waiting lists.

4. Essentially, the bill does nothing new. It describes the status quo in terms of the service delivery structure. Where, then, is the reform? The apparent "reform" consists of more tightly proscribing funding mechanisms which will benefit certain agencies and increasing the police power of the Secretary of SRS over non-profit, community service agencies. Neither of these measures seems to be necessary. They certainly do not constitute "reform", not is it clear how these will benefit people with disabilities in terms of creating sufficient, cost effective, and appropriate service options in the community from which people can select.

To begin any kind of meaningful "reform" which will benefit people with disabilities, the bill would need to contain the following features:

1. All providers of service meeting state and federal standards (not private standards set by designated private agencies) be allowed to directly receive the funds and provide any allowable service.

2. Every person desiring services be informed of All available options including addresses, phone numbers, contact persons and other relevant information.

3. Updated lists of people waiting for services be provided to all qualified agencies. (A simple waiver could be signed indicating consent to being listed).

4. "Reform" language should be used in the bill affirming the intent of the bill is to improve the lives of people with disabilities by providing services in the most integrated setting appropriate. This affirms the civil rights of people with disabilities. It affirms the state's intentions respecting the rights of people with disabilities.

5. Quality is enhanced when consumers have more choices. The best way to judge a service is by asking about the satisfaction of the consumer. The bill should set up a mechanism for systematic consumer reviews of the effectiveness and quality of the services. Put the monitoring and control of quality into the hands of the people using the services and we will have high quality services and happy consumers.

On a final note, there is a great promise for instituting true reform and creating an array of options which are cost effective and of quality. Our agency has continued to network with other community agencies. We are committed to increasing cooperation and coordination amongst service providers with the purpose of increasing the independence and choices available to people with disabilities. Putting all agencies on an equal footing with regard to funding and service provision will enhance quality and increase coordination. Equal footing will decrease waiting lists and increase consumer satisfaction.

Thank you for considering these remarks.

LINK INC.

Living Independently in Northwest Kansas

1310 Walnut
(913) 625-6942(V/TDD)

Hays, KS 67601
(913) 625-6137 (FAX)

Testimony to
House Select Committees on Developmental Disabilities
Rep. Jo Ann Pottorff, Committee Chairman
Submitted by Brian Atwell, LINK, Inc.
February 15, 1995

Thank you for this opportunity to discuss the possible options for people who have developmental disabilities. My name is Brian Atwell and I am the Director for Living Independently in Northwest Kansas (LINK). LINK is a Center for Independent Living working with people with disabilities in Northwest Kansas.

I am opposed to HB2458 as it is presently written. This bill re-affirms that CMRC's are the only agencies that can provide services to people with developmental disabilities. People with disabilities want to have choices, and should have a choice of providers. Centers for Independent Living are consumer controlled, and should also be able to provide services to people with developmental disabilities. Our experience and understanding shows that "Affiliation Agreements" can be very restrictive and offer no choice for the consumer.

Thank you for this time.

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Attachment 5

TESTIMONY TO
THE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES

Joann Pottorff, Chair

Members of the Select Committee, Chair Pottorff and others:

I am Ann Branden from Independence, Inc. in Lawrence. Independence, Inc. is an Independent Living Center that serves people with disabilities in Douglas, Jefferson and Franklin Counties. We provide services that empower persons with disabilities, including persons with developmental disabilities, to live independently in the community.

I am here today to testify on House Bill No. 2458 - the developmental disabilities reform act. First, I would like to commend the framers of the bill for the stated purpose of the act - providing services and supports which foster increased independence, integration and inclusion of persons with developmental disabilities in the community, access to an array of services and supports and the same opportunities, dignity and respect as persons who do not have a developmental disability. In order to meet the purpose of the act, it is necessary to provide consumers with choice, not just of services and supports but choice among organizations to access services and supports. We would like to urge the committee to provide the widest array of consumer choice possible.

Currently, a consumer with a developmental disability must seek access to services and supports through a community developmental disability organization (CMRC). There is no choice in how to access community services. There are, however, other organizations that can and do provide services to persons with developmental disabilities. Independent Living Centers (ILCs), for example, are an alternate choice to access community services. There are 12 Independent Living Centers in Kansas that provide an array of services to people with physical, developmental, mental health and sensory disabilities. ILCs also serve persons with dual diagnoses, who often fall between the cracks in the system because not all organizations are willing to provide services. ILC services are all designed to empower consumers to live independently in the community. Since provider choice is available in most areas of Kansas, persons with developmental disabilities, or their family members, should be able to choose what provider they want to use to access community services and supports.

This bill is about increasing independence and inclusion of persons with developmental disabilities in the community. The most direct route to accomplishing such a purpose is choice. We urge the committee to include the greatest array of choice in this bill as possible, including choice of providers through which to gain access.

Thank you for the opportunity to testify on this matter.

House Select Committee on
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Personal Care Attendant (PCA) Management

Independence, Inc. serves as a business agent for eligible persons with disabilities who wish to direct their own PCA services under the Kansas Medicaid HCBS Waiver Program. Management includes: preparation of biweekly paychecks, filing of related payroll returns and taxes, and worker's compensation coverage. In addition, instruction on hiring, firing, and training PCAs is available. For more information, ask for the PAS Systems Manager at the main office.

Resource Library

Books, video tapes, magazines, newsletters and other publications dealing with disability-related issues are available for use by consumers, students, and the general public. Many items may be checked out for home use.

Human Diversity Statement

Independence, Inc. would like to express a warm welcome to all persons with disabilities and their families. We encourage men and women of all income levels, people of color, people of all ages, individuals who are lesbian or gay, and all culturally-diverse groups to join us. We appreciate diversity and strive to make our Center as multi-cultural as possible.

People We Serve

Independence, Inc. serves anyone with a physical or mental condition that limits one or more of life's major activities, or who is regarded as having such a disability. This includes individuals whose disability is controlled by medication or is in remission.

Independence, Inc.
1910 Haskell Avenue
Lawrence, KS 66046

8 a.m. to 5 p.m.
Monday through Friday

Main Office	**841-0333**
TDD	**841-1046**
Transportation	**843-5576**
or	**843-5585**
Computer Lab	**841-1067**
FAX	**841-1094**

Independence, Inc. does not discriminate on the basis of race, color, national origin, sex, creed, age or disability in admission or access to, or treatment in, its programs or activities. If you believe you have been discriminated against, please contact the Director, the Section 504, Title VI, VII, IX and ADA coordinator at: Independence, Inc., 1910 Haskell Avenue, Lawrence, KS 66046.

INDEPENDENCE INCORPORATED

Empowering people with disabilities to control their own lives and advocating for an integrated and accessible community.

LAWRENCE

INDEPENDENT LIVING RESOURCE CENTER

Advocacy

Information about legal rights of people with disabilities is provided. Our staff work with consumers and the community to ensure that people with disabilities acquire and maintain their legal rights and benefits.

Benefits Assistance

Assistance with identifying and applying for public benefits including Social Security is available. Help with filling out application forms and advocacy with other social service agencies is provided to individuals meeting eligibility requirements for benefit programs.

Technical Assistance

Information on architectural or environmental accessibility for people with disabilities is available to households, businesses, and those in the building industry. Additional information is available on local, state, and federal non-discrimination laws that cover people with disabilities. Specific information is available regarding the Fair Housing Amendments Act of 1988 and the Americans with Disabilities Act of 1990.

Housing Assistance

Information is provided to people with disabilities about accessible and affordable housing in the Lawrence area. Training to find and keep housing is available.

Information and Referral

Staff are available for assistance with general problem-solving. Information about community services and referral to other programs is available upon request.

Accessible Housing Program

Funded by the City Community Development Department, this program pays for accessibility modifications needed in housing rented by people with physical disabilities.

Counseling

Individual counseling is available to address issues related to independent living including: adjustment to disability, coping with stress, crisis intervention, relationships and family issues. Our services may also teach, support, and enhance social and communication skills. Referrals to other counseling services are available.

Independent Living Skills

Group and individual instruction is provided in life skills such as money and household management, personal care, consumer control and employment preparation. The goal is to increase the self-reliance and independence of people with disabilities.

Volunteer Peer Counseling

Individuals with disabilities who have gained knowledge and coping skills assist others in coping with their disability-related experiences. Trained volunteer counselors provide information, resource referral, emotional support and training.

Support Groups

Independence, Inc. hosts or sponsors various support groups for people with disabilities for educational and/or social enjoyment. Contact us for dates and times of these groups.

Adaptive Equipment

A limited selection of adaptive equipment including crutches, ramps, wheelchairs and walkers is available for short-term loan.

Microcomputer Training

The Computer Learning Center offers individual and class instruction in microcomputer applications to any person with a disability. Classes in word processing, relational data base, and electronic spread sheet programs for IBM compatible computers are regularly scheduled. Students are given the opportunity to participate in workshops on job-seeking skills, resume writing and interviewing. In addition, on-the-job coaching can be arranged.

Transportation

Rides on accessible buses to medical or other appointments and for shopping or other needs may be scheduled with the transportation office. Rides must be scheduled in advance; a donation is requested but not required. For more information contact the transportation office at 843-5576 or 843-5585.

Community Education and Outreach

Center staff and consumers are available to speak to civic groups, schools, churches and others to increase awareness of the needs of people with disabilities. The Center's monthly newsletter *Ahead of the Times* publicizes information on disability issues to consumers and other interested persons or organizations.

CLASS

P.O. Box 266 • Columbus, Kansas 66725 • (316)429-1212

TESTIMONY
TO THE
HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES
JO ANN POTTORFF, CHAIRPERSON

BY
ROBERT L. CLARK, PRESIDENT/CEO
CLASS LTD

FEBRUARY 15, 1995

Chairperson Pottorff and Members of the Select Committee, I appreciate the time on your agenda this afternoon to advocate for the enactment of HB 2458, introduced by this Committee as the Developmental Disabilities Reform Act.

My name is Bob Clark. I am the chief Executive Officer of CLASS LTD in Columbus. We are a comprehensive, Community Mental Retardation Center serving the counties of Cherokee, Crawford, Labette and Montgomery. CLASS was incorporated in 1975, beginning with operations in Cherokee and Labette Counties. Crawford County joined in 1976, and Montgomery county in 1984.

As of January 31, 1995, CLASS was serving 226 individuals on a regular, daily basis, with a total of 29 people awaiting our services, which includes both institutional and community waiting list referrals. To serve these individuals, as of February 1, we had employed 147 full-time, 63 part-time and 46 substitute personnel. Currently, our annual expenditures are running the rate of $5.35 million and our annualized income is running a rate of $5.2 million. Thus, we are losing money!

House Select Committee on
Developmental Disabilities
2-15-95
Attachment 7

"Serving people with disabilities in their quest for quality of life"

In the first six months of our fiscal year, our revenues were derived from the following sources, by percentage:

State government grants and services contracts - 77.6%

County government mill levies - 7.57%

Earned income and service fees - 10.26%

Miscellaneous revenues - 4.57%

Over the past five years, CLASS has doubled the number of people served on a daily basis; we have tripled in the number of staff employed to serve our increasingly severely-impaired clientele with multiple needs. During that same period of time, our funding pattern has changed from predominantly State and county grants and industrial sub-contract revenues to, primarily, State purchase-of-service fees. At the present time, our HCBS revenues account for 51.5% of our current annualized revenue. Our industrial sub-contract income account has dropped from roughly 15% or our budget, five years ago, to roughly 5% now. The share of our budget funded by mill levy has dropped from 14% to slightly more than 7% over that same period. These changes reflect the de-emphasis on sheltered, industrial sub-contract work as the <u>primary</u> vehicle for our day habilitation and work training services.

As of December 31, 1994, <u>64%</u> of the 146 individuals receiving Employment Services from CLASS are working in "inclusionary sites", in the community, and do not work inside one of our sub-contract workshops. At that same date, <u>78%</u> of the 106 people served in our Community Living Services program were living in their own home of choice, in the community, rather than in a group home operated by this agency.

As we have made this substantial shift to more individualized and inclusionary services, and de-emphasized our "congregate" work and residential care services, our earning of industrial sub-contract revenue has dropped significantly and our dependence on the purchase o service fees, paid by the State through the HCBS/MR Waiver mechanism, has increased.

Five years ago, CLASS was unable to serve anyone who was not ambulatory or fully toilet-trained. Today, we serve individuals who require complete physical care, and diapering 24 hours-a-day, in non-ICF settings. With the support of Public Health Nurses from our county health departments, we are able to serve those individuals who were, at one time, considered "too medically fragile" to be served outside of an institutional setting.

I recite the foregoing simply to emphasize to you the substantial and rather mind-numbing pace of change which has occurred within our Kansas community services system over the past four to five years! Since the landmark study in which you, Rep. Pottorff, participated in the fall of 1990, and which resulted in the Five-Year Plan presented to the 1991 Legislature, the pace of State-initiated change, and the acceleration of available funding resources, has led to unprecedented growth in the services offered in Southeast Kansas.

I am here, today, to advocate the enactment of HB 2458, generally as introduced, because of these rather rapid developments in our community services system since the watershed events of 1990-91. We believe that it is rather amazing that State support for our community services system has grown to an estimated FY 95 expenditure of over $55 million of State-administered State and federal funds, without any complete codification of state policy, philosophy and direction by statute. Indeed, Kansas has been fortunate to have the MH&RS Division leaders who have been present for, at least, the past five (5) years to guide and facilitate the development of services in accord with the 5-year plan in a very positive direction, based solely on annual appropriations act authorizations and guidelines. Indeed, the latitude which has been granted by the Legislature to the administration is rather amazing and implies a high level of confidence by the Appropriations and Ways and Means Committee's members, at least, in the administration of these funds by SRS and MH&RS.

One of the over-arching concerns of the elderly parents whose adult children are being served by CLASS is that the Kansas services structure and delivery system be sufficiently developed and reliable, in the long term future, that the guarantee of the availability of community services will "outlive them" and provide the legal assurance of needed services, guidance and supports for their children long after they are gone. Thus, our service system needs both the <u>dynamic growth</u> and change components, which have been realized over the four or five years, coupled with the <u>stability</u> of State-established policy, by law, on the intent of the State of Kansas to provide for its citizens who have developmental disabilities and who need varying degrees and lengths of assistance in order to assure that they have the <u>opportunity</u> to develop to the greatest degree of their individual potential. Parents naturally want their child to live as free, productive, and secure a life as is possible, in the most appropriate community settings consistent with their capabilities, resources and personal preferences.

It is for these very reasons of our need for continued dynamic development in positive service directions--added to the need for the stability and assurance to families who fear that the reduction of institutional beds will mean a reduction of the State's commitment to the long-term needs of those with serious disabilities--that a formulation in statute of the State's policies, intentions, and directions is both timely and appropriate.

In 1966, I had the opportunity to serve as the first Executive Director of the Greater Omaha Association for Retarded Citizens. During the period of 1967-1970, I served as a member of the Governor's Committee which developed the Nebraska Plan for the initiation of comprehensive community services, throughout the state. At that same time, I led the founding of the first regional, community services system in America offering comprehensive services to the mentally retarded. Since 1970, this system has been known as ENCOR. My experience in

Nebraska, when we were creating community services "from scratch," convinced me that the significant commitment of local and State public resources to the creation and operation of a community services system requires the establishment of well-deliberated public policy, with strong legislative input, because of the legislative responsibility for appropriating the bulk of the funds necessary to make those services possible. This legislative commitment to community services must be coupled with dedicated and knowledgeable administrative implementation by the Governor's designated representatives, working in cooperation with local public officials and private service providers in order to establish and expand the necessary network of comprehensive services--with user choice--which will provide the assurances and the security of long-term and appropriate services which both individuals with developmental disabilities and their aging family members require.

I believe that Kansas has been most unusual, and most fortunate, to have developed the existing community services system, with as few "glitches" as have occurred over the past 15 to 20 years, <u>without</u> the existence of a comprehensive policy approach in law, reflecting legislative deliberation on the structure for the administration of significantly State-supported services.

I will comment only generally on a few sections of your bill, since KARF will be submitting detailed recommendations for possible amendments, which I and CLASS fully expect to support.

My review of the Bill, as introduced, indicates that Section 3 generally provides sufficient authority, oversight, and quality controls to the SRS Secretary. Section 3 would appear to provide sufficient authority to the Secretary to continue the positive directions of community service development which we have experienced over the past several years. For better or for worse, it avoids the language of a "mandate for services," such as we find in the education laws for those requiring special education services. It will be the Secretary's responsibility to assure

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that the needs which have been identified by the local service provider network, state-wide, are accurately reported, annually, to the Legislature so that your future deliberations will give you the opportunity to fully understand the needs for services, and financial support for those services, in the various communities across the State.

Section 5 provides protections for the local providers, such as our organization, in that we will have at least a biennial review of the <u>actual costs</u> of providing the services, which we have been asked to provide, so that we can be fairly compensated for the actual costs we have incurred in providing the appropriate, community-integrated, individualized services which we have been urged by MH&RS to develop. At the present time, our current HCBS/MR reimbursement rates are clearly insufficient to support more than "congregate care services" for nearly all of those we serve who are not on individually-negotiated rates. Thus, for every person we move out of a workshop setting or group home into a "supported employment" or an individualized living placement, in their own home of choice, we expect to take a loss based on our current reimbursement from the State of Kansas. We cannot continue to do this without serious reductions in the quantity and quality of services we not offer. Thus, those of us who provide the bulk of the services at the community level see the assurances of Section 5 as critical to our continued economic viability, and our ability to compete with other employers for the caliber of people we need to deliver quality services. We also believe that quality assurance for services standards must be clearly addressed, as well as the opportunities for all persons served to have a reasonable choice of who will provide the services needed, based upon the availability of qualified providers who can meet licensing and other service competency requirements in each service area.

I understand that some concern has already been expressed about the powers provided in Section 6 to the Secretary of SRS to intervene in CDDOs which have been found to have failed to comply with the requirements, standards, or rules and regulations proposed pursuant to this bill, or any other provisions of law. SRS takeover of a private, not-for-profit entity, as proposed, needs to be rethought and deleted.

In summary, we CLASS LTD look forward to the enactment of HB 2458, substantially as this Committee has introduced it. We would hope to avoid any amendments designed to impose a non-system of community providers, since we believe that the Bill adequately reflects the current evolutionary state of our community service system and its relationship with SRS and MH&RS. In addition, it provides additional enhancements and safeguards for the further development of community services for those who require the services, their families, local service-providers and the State of Kansas.

Finally, we look forward to the enactment of a refined HB 2458, which coupled with additional appropriation authorizations by both the House and the Senate, will give us the financial resources to fully implement the forward-looking philosophy and intent of HB 2458. Both this Bill, respecting the State's policy, and the annual appropriations process which must provide the fuel to realize the goals and directions specified in this Bill, will be <u>essential</u> for the further, more comprehensive, development of services for those with developmental disabilities in Kansas.

Respectfully submitted,

Robert L Clark

Robert L. Clark

President/CEO

cc: Board of Directors