

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES.

The meeting was called to order by Chairperson Carlos Mayans at 1:30 p.m. on February 6, 1997 in Room 423-S of the State Capitol.

All members were present.

Committee staff present: Emalene Correll, Legislative Research Department  
Norman Furse, Revisor of Statutes  
Lois Hedrick, Committee Secretary

Conferees appearing before the committee:

Jan Root, President/CEO, Southeast Kansas, CLASS LTD  
Kara Walters, Residential Director, Cottonwood, Inc.  
Steve Gieber, Employment Services Director, Occupational Center of Central Kansas, Inc.  
Thomas Laing, Executive Director, InterHab, Topeka

Others attending: See Guest List (Exhibit 1)

Chairperson Mayans welcomed conferees and visiting nurses and others and expressed his and the committee's appreciation for the work they do. He then announced that the hearing and possible action on **HB 2137** [expanded first dollar coverage for immunizations] and the committee's proposed amendment will be heard on Monday, February 10.

Chairperson Mayans then welcomed Jan Root, President/CEO of Southeast Kansas, CLASS LTD., Columbus. Ms. Root spoke on the Community Network for Support and Services provided to those persons with developmental disabilities. She described the history, the current system, and efforts underway to implement developmental disabilities (DD) reform; and listed issues and challenges the organization faces today. (See testimony, Exhibit 2). Ms. Root described the struggle the organization undergoes to determine need vs. choice and then determine how services are rationed. She said it is a matter of changing thinking of how the system has been, what is available now in programs and money, and how to meet the ever-changing needs of the people.

Kara Walters, Residential Director for Cottonwood, Inc., Lawrence, described the activities of Cottonwood and stated it is the Community Developmental Disabilities Organization for Douglas and Jefferson Counties. It serves as the single point of entry into the DD system for the area. Ms. Walters described the work of her organization and her views of the trends and challenges facing community-based residential services. (See her testimony, Exhibit 3).

Chairperson Mayans then introduced Steve Gieber, Employment Services Director, Occupational Center of Central Kansas, Inc., Salina. Mr. Gieber provided a description of the importance of employment options for the developmentally disabled; and directed attention to the charts on his written testimony describing the kinds of services, where the people were placed, and the kinds of employment provided 883 disabled through the 23 InterHab agencies in 1995. (See testimony, Exhibit 4).

Tom Laing, Executive Director, InterHab, Topeka, was welcomed by Chairperson Mayans. Mr. Laing described the historic development of the network of community mental retardation centers in the 1960's, which is the system of today. He then outlined elements of today's system; the emerging issues to improve the lives and employment services of the developmentally disabled (funding being the paramount issue); and set out a summary of issues yet to be resolved with legislators and state administrators. (See testimony, Exhibit 5).

Chairperson Mayans thanked all of the conferees for their testimony.

The meeting was adjourned at 2:55 p.m.

The next meeting is scheduled for February 10, 1997.

HOUSE COMMITTEE ON HEALTH AND HUMAN  
SERVICES COMMITTEE GUEST LIST  
FEBRUARY 6, 1997

NAME	REPRESENTING
Tracy Webb BCSN	Bethel College Nursing Dept
Gwen Goder BCSN	" "
Katherine Jost BCSN	" "
Jennifer J. Prunty BCSN	" "
Janet J. Jara BCSN	" "
Mark Jandrew BCSN	" "
Elizabeth Lam BCSN	" "
Jane Wuthnow BCSN	" "
Keith Haxton	
Evelyn E. Parker RN	AORN 1702 Wichita, KS <sup>KSNA District 6</sup>
Karen Skalsky DCC SN	Dodge City, Community College Nursing School
Alyc Okwara	DCCC
Connie Nguyen	DCCC
Duane Rankin	DCCC Nursing Program
Debbie Collins	JCDS
Virginia Cobb	JCDS
Johnnie Wintz	BUSN
Tracy Simms	Baker University School of Nursing (Topeka Campus)
Kim Springer	Baker University (Topeka Campus)

HOUSE COMMITTEE ON HEALTH AND HUMAN  
SERVICES COMMITTEE GUEST LIST  
FEBRUARY 6, 1997

NAME	REPRESENTING
Mary T. Zahner	Wichita-SEDC, County Dept. of Comm. Health
Cay Lynn Nelson	Wichita-SEDC, HHS HL Dept / KBCCZ
Barbara Stoeck	Washburn U. School of Nursing
Debbie Ramirez	Washburn University School of Nursing
Josephine Giedman	The Arc of Atchison Co.
Dudy Oyer	The Arc of Atchison County
Barbara Parker, RN	Kumed Ctr. Fam. Nurse Practitioner Program
Janelle O. Magee	Anita Student Nurses
Sandra Mitchell	WCC - School of Nursing
Traci Popp	HCC School of Nursing
Adelle Thompson	HCC School of Nursing
Jana Reiter	HCC School of Nursing
Kendra Ralston	Butter CCC Nursing
David Lawson	Butter CCC Nursing
Larrie Ann Brown	KHA
Darin M Conklin	KPhA
C Morale, II	Mary Griggs S.O.N.
Gret M. Melvin	FSU School of Nsg.
Lisa Pretyer	KSNA

HOUSE COMMITTEE ON HEALTH AND HUMAN  
SERVICES COMMITTEE GUEST LIST  
FEBRUARY 6, 1997

NAME	REPRESENTING
Kelli Willard	Baker University (Topeka campus)
Richard Schutz	SRS/KRS
Norma Nightingale	Dodge City Community Col.
Janell Witt	Dodge City Community College
Barbara Butteroff	Abilene, OCK INC.
Dorothy Moralito	OCK, INC. - Salina/Abilene
ARLINDAVIS	" "
Michael Anderson	" "
Duane Elliott ND	" "
Koylyeth	KSNB
DANREPP	BUTLER CO. COMMUNITY COLLEGE
Mwendolyn Stubbaker	Butler Co. Community College
Carol Mayer	Butler Co. Comm. College
Annell Luckett	Butler Co. Com. College
Regina Stotel	Southwestern College Winfield
Kelly Paris	Avila Student Nurse
Sara Mars	AVILA COLLEGE
Susan M. Baker	Heim + Weir
Amy Campbell	R. Rice Law Office

HOUSE COMMITTEE ON HEALTH AND HUMAN  
SERVICES COMMITTEE GUEST LIST  
FEBRUARY 6, 1997

NAME	REPRESENTING
DIANA SNOWBALL R.N.	SMOKY Hill FAMILY PRAC - SALINA
Penny Mattson R.N.	Salina Regional Health Center - HWY
Carrie Tholen RN	Salina Regional Health Center - HWY
Rebecca Vash SN	Fort Scott Community College
Sharon Jones	SICK
Jim Magee	Independent Connection / OCCR
Betty VanBaskel	Achievement Services for NEK
Elizabeth M. Stone	Achievement Services for NEK
Rita Madden	Achievement Services for NEK
Brad Walker	Achievement Services for NEK

Presentation to House Committee on Health and Human Services  
February 6, 1997

**Topic: The Community Network for Supports and Services**

Good afternoon and thank you for inviting me to make a presentation on the community network for supports and services for Kansans with developmental disabilities.

My name is Jan Root. I currently work for an organization in Southeast Kansas, CLASS LTD. CLASS LTD is designated as a Community Developmental Disabilities Organization (CDDO) by the State Division of Mental Health and Developmental Disabilities. Our administrative office is in Columbus. My job title is President/CEO, having held this position for the past one and one-half years. I have worked for CLASS LTD for a total of seventeen years in various capacities including community living manager and rehabilitation director. Prior to coming to CLASS LTD, I worked for a developmental disability organization in Wichita, KETCH, and prior to that at Parsons State Hospital. I have in total over thirty years of experience with twenty-seven of them in community services.

**DEVELOPMENTAL DISABILITES SERVICES - HISTORICAL REVIEW**

In the last thirty some years, I have seen the field of developmental disabilities go through some dramatic changes. When I first started working in this field, many of the existing community services were developed and run by parents with children with disabilities frustrated by the lack of any activity for their adult children to do during the day. Parents and volunteers started community services in garages, basements and store fronts. The activities consisted, to a large extent, of socialization opportunities, arts and crafts; whatever these determined, hard working persons could think of that seemed to be appropriate.

During the seventies, and as a result of advocacy by parents and others, community services for persons with developmental disabilities began to expand. Developmental disabilities organizations began to spring up around the state. I can remember visiting a number of these organizations. They were often housed in older, poorly lit buildings. There were very caring staff working with persons with fairly mild disabilities for the most part. Efforts to assist individuals to find work opportunities and group living arrangements were among the primary thrusts of services. Individuals with more severe mental retardation or more challenging physical disabilities were typically not served in the communities. They were either still at home with little to do or in state institutions.

The eighties brought about larger more sophisticated organizations. Many parents and family members were beginning to be less involved in the day to day operations—the “professionals” were administering the programs. Funding was tight and there were long waiting lists of individuals wanting access to community services. Community service providers began to individualize services and began to serve persons with more severe

disabilities. These changes came about as a result of many different factors, but one of the most significant factors was Kansas obtaining its first Medicaid Waiver, the Home and Community Based Services (HCBS) funding. The waiver was an expansion of funds made available for persons with more severe disabilities and allowed individuals to receive services on a long term basis. The funding sources, including HCBS, vocational rehabilitation and state general funds remained insufficient to serve all those requesting services. Waiting lists continued to grow.

### **DEVELOPMENTAL DISABILITIES REFORM ACT AND THE CURRENT COMMUNITY SERVICE SYSTEM**

With the passage of the Developmental Disabilities Reform Act (DD Reform Act) in 1995, the field of developmental disabilities has seen the most dramatic changes yet. Two primary objectives of the act were to develop a comprehensive, coordinated service system in Kansas for individuals with developmental disabilities and to provide them with choices in selecting their service provider. These objectives seemed to have been accomplished. There are 28 CDDOs in the state, each serving a designated number of counties. Each CDDO is responsible for making available a wide array of services as determined by the persons presenting themselves for service. The CDDO may provide services or may affiliate with other service providers or both. The majority of CDDOs both provide services and affiliate with other service providers operating within their service area. With the emphasis in the DD Reform Act on making choices available to the individual for service provider, we have seen a number of community service providers requesting affiliation including not-for-profit organizations as well as for-profit organizations. Many of these affiliate organizations are very small, serving only a few individuals and many are families providing service to their adult child or through what is called "self-directed care" arranging for an individual to come into their home and provide service to their family member with a disability.

Another significant change I have seen in the last several years and particularly in the last year has been the support and commitment from the legislature, SRS and the developmental disabilities service providers to reduce the population in state hospitals and make more funds available for community services. The additional funds made available in the CDDO contracts for community services has had a major impact on waiting lists. The last information I have from MH&DD is that there are less than 100 adults and approximately 50 families state wide awaiting services at this time.

### **CLASS LTD**

CLASS LTD is the CDDO for the counties of Montgomery, Crawford, Cherokee and Labette. We currently provide or arrange services for over 360 children and adults. The services offered in our area have expanded over the years from a few rather rigidly defined services to many varied and loosely defined services. The services we offer are those requested by the individual or the family. They include service coordination, sometimes called case management, employment services, community living services, respite, and in-home services such as supportive home care and personal attendant. We also help individuals access services such as home modifications and health care. We

administer the family subsidy program and have 26 families receiving cash assistance currently. **Our aim is to provide the services the person needs to remain in the community and that will enhance their life to the extent we have the technology and resources.**

We have affiliation agreements with six community providers. They include SKIL, the local independent living center; SEKRS, a respite service provider; Kaw Valley Center and The Farm, supportive family living providers; Life Patterns, a respite and supportive home care provider and a payroll agent for families; New Beginnings, a comprehensive service provider and New Hope, a community living services provider. We have had several other organizations request information on affiliation. I see this as a trend with more and more organizations providing services across the state through affiliation with the local CDDO.

### **IMPLEMENTING DD REFORM**

During the last year, CLASS LTD has worked to understand fully the Developmental Disability Reform Act (DD Reform) and the accompanying rules and regulations. We have developed our own set of policies and procedures with input from a number of interested individuals and groups. They have been sent to the Commissioner of MH&DD for approval. These implementing procedures include:

- How persons access services in our area, including ICFs/MR, state hospitals and community services
- Quality assurance and monitoring process
- The Affiliation process
- How services are coordinated
- Non-discrimination provisions
- Dispute resolution process
- How funds follow the individual when they change service providers
- The role of the Community Council
- Management of the Waiting List

CLASS LTD has had many of the required procedures in place for years, but they may have needed some expansion or modification. We have a good deal of experience with some of these procedures and can attest to their effectiveness. There are several of the procedures we did not have previously and have had to develop them, such as the procedure for screening individuals for state hospitals or an ICF/MR. It will take some time to evaluate their effectiveness and modify them as needed.

We very recently completed the new licensing process specified in the DD Reform rules and regulations. We received word that we received full licensure. Although we did not encounter any difficulty with the licensing process, it was definitely more prescriptive than it has been for many years.



## ISSUES AND CHALLENGES

Each CDDO has its own unique set of challenges facing it today. I will address the challenges CLASS LTD has identified which seem to closely relate to those of my colleagues around the state.

A major challenge before us currently is to fully implement the DD Reform Act and its rules and regulations. We will need time to test the procedures we have developed to implement the Act, determine their utility in our service area and modify them as needed.

A second immediate challenge is to serve or arrange to serve all those who are eligible for and require service. With the increased funds available CLASS LTD has seen significant growth in the number of individuals served. One year ago we had approximately 270 individuals on our census. Today the number of children and adults served in our area is over 360. The challenge is to serve individuals within the 60 day requirement and at the same time develop services that meet the unique needs of each person.

Some of the individuals who are found eligible for service require very collaborative efforts to plan and implement services that offer choices and at the same time provide for their safety and address their needs. CLASS LTD has a long history of providing services to individuals with multiple and severe disabilities and associated problems. We have seen however, an increase in the number of individuals applying for service who present their own unique challenges. Some of these individuals have a dual diagnosis of mental illness and mental retardation which creates the need for including in their service plan the expertise from mental health services. Some of the individuals presenting unique challenges are those with a history of encounters with law enforcement and some of the individuals have very severe physical disabilities. We have developed a number of excellent working relationships with community organizations such as health departments, home health organizations, mental health centers, law enforcement agencies, community housing groups, Parsons State Hospital, etc. We work to enlist the support and involvement of family members whenever possible. It is only through effective collaboration that the DD Reform Act and its objectives can be realized.

Providing services in the most cost efficient manner is a challenge to service providers. Determining the services required by an individual rather than what they may want is definitely a challenge. Educating the individual and the family regarding needs versus wants is sometimes difficult. Developing systems that allow us to track costs of services accurately has taken on new significance and is imperative to the financial management of CDDO funds.

With the current rate of expansion of services it is difficult recruiting the number of qualified staff needed. Most organizations have modest pay scales and retaining good staff is sometimes difficult. We are struggling with better methods to recruit staff, train them in the many areas needed to provide quality services and keep them from seeking jobs elsewhere.

We continue to have individuals with disabilities who want to work. Current funding for employment services is limited, especially for those with more severe disabilities who require long term support and services. We are trying to develop natural supports on the job and be more creative with the funds that are available.

Developing systems to monitor CDDO provided services as well as to monitor affiliates presents new challenges to the CDDO. Procedures and systems for these monitoring functions require much staff time. Most CDDOs have had to add personnel to accomplish this.

I believe that 1997 offers more opportunities for persons with developmental disabilities than any time since I have worked in the field. Individuals and their families have easier access to services, more choices regarding the services they receive, more and better technology available to them, and assurances that funding will follow them as they change service providers or locations within the state. Service providers have a number of issues and challenges before them, but the history of the community service provider system in this state has shown that with the continued support of the Legislature and SRS/MH&DD these issues and challenges will be met.

2-6-97

Testimony on Community Based Residential Services in Kansas, presented to the House Committee on Health and Human Services.

Thank you, Mr. Chairman and Members of the Committee.

Good afternoon. My name is Kara Walters. I am the Residential Director for Cottonwood, Inc. in Lawrence, Ks. I would like to tell you about residential services for people with developmental disabilities in Kansas. This is the first time I have given testimony, so please bear with me.

Many individuals with developmental disabilities are served in ICF/MR's. ICF/MR's are able to provide significant medical and behavioral support, as mandated by federal regulations. ICF/MR's come in three different sizes: small-bed, medium-bed, and large bed. Many organizations provide community based services in small bed ICF's that look no different than the other homes in their neighborhoods. Community Living Opportunities, an organization providing services in DG and JO counties, offers a Teaching Family service model in their ICF's. The Teaching Family Model emphasizes incidental teaching, capitalizing on the many opportunities in their consumers' lives to improve skills and gain new knowledge. CLO recently instituted "couple-based" Teaching Family services. A married couple serves as the primary care providers for a small number of clients. This approach fosters a sense of family and community for the individuals being served.

Community based group homes also come in many different sizes, and with varying staffing patterns. Community integration is a predominant value. Group homes are found in all types of residential neighborhoods. Many organizations own group

homes, while other organizations have chosen to use rental stock exclusively. While compromise is necessary in any communal living arrangement, it is possible to pursue individualized person-centered objectives with great success in these settings also. These arrangements are often less expensive, due to combined funding, shared staffing, and economy of scale purchasing.

For a client receiving supported living services, the individual and the team, consisting of family members, advocates, agency staff, etc., meet together to design the person's support plan. Supported living services are ideal for individuals whose support needs are more successfully met in settings with fewer housemates and more intensive staffing patterns. If an individual needs many hours of support, then supported living services are a more expensive option than group living. Also, individuals receiving supported living services generally pay for all of their living expenses, so this arrangement is often more expensive for the consumer as well.

Semi-independent living services are also available. Individuals live in their own apartments or houses, and receive assistance for their daily activities. Staff support ranges from just a few hours a week up to 10-15 hours.

Traditionally, people with DD have been excluded from home ownership due to limited incomes, little or no credit history, and considerable support needs. However, through the "Home of Your Own" program, interested individuals work with local lenders, consumer credit counselors, realtors and service providers to find creative financing and down payment options. Funding for the "HOYO" program is provided by the U.S. Dept. of Health and Human Services.

I would like to tell you a little bit about the organization I work for.

Cottonwood Inc. is celebrating its' 25th anniversary this year.

C'wood is the Community Developmental Disabilities Organization for Douglas and Jefferson Counties. As defined by the Developmental Disabilities Reform Act, C'wood serves as the single point of entry into the DD service system for the area. C'wood works closely with affiliated providers to meet the service needs of people with DD.

C'wood also directly provides a wide variety of services to adults with DD. C'wood offers Work Services, where individuals earn commensurate wages by working on varied sub-contracts in a supportive setting. This work is offered at the main facility, and in industry based work sites. We also offer a Work Enrichment option, which allows individuals with greater needs the choice of working according to individualized schedules in combination with opportunities for community exploration. C'wood's Employment services assists consumers in job searches, matching an individual's interests and skills with available jobs in the community. Job coaches provide as much support as needed to ensure a fair opportunity for success. C'wood's Support Services Dept. provides comprehensive casemanagement and health support services to our clients.

Residentially, C'wood provides direct services to 100 consumers in approximately 40 different sites throughout Lawrence. Living arrangements vary from single person dwellings to six individuals living in a group home. We are providing services to nine individuals who are funded through the Community Integration Project. As the state hospitals continue to downsize, we will work on support plans to serve additional people currently residing there. Support needs for our consumers range from 1-2 hour per week of staff assistance to 24-hours a day, including overnight awake staff.

Consumers served by C'wood have rich social interactions with other members of the Lawrence community. Lawrence is a place that values diversity, and has proven to be an inclusive and supportive community.

Most of our clients receive funding for services through the Medicaid “Home and Community Based Services” waiver. The amount of HCBS funding is determined by the “Developmental Disabilities Profile” assessment, which measures an individual’s support needs and assigns a tier rate for funding. Other funding sources include state grant funding, county mill levy, private donations and fee for service income.

C’wood’s adoption of a “person-centered planning” system geared toward meaningful individual outcomes has resulted in many realized dreams and desires for the persons we serve. Action plans have included goals such as attending a Broadway musical, painting a bedroom pink, renting a house instead of an apartment, and learning about the responsibilities of marriage. While not all action plans are achievable, consumers learn self-advocacy skills, broaden their horizons, and become aware of available choices and inherent consequences resulting from increased self-direction.

In closing, I’d like to share with you some of the future trends and challenges facing community based residential services.

Consumers will continue to become increasingly self-directed. They will have more choice and control over the services they receive, including increased involvement in and responsibility for hiring and training their staff. Along with increased autonomy comes responsibilities associated with employment, such as recruiting qualified staff, finding satisfactory coverage for vacancies, and utilizing employment practices that are non-discriminatory.

It is apparent that the relationship between the consumer and direct service staff is the foundation of service provision, not an end result. Direct service staff are expected to provide respectful, sophisticated, person-centered services at all times. These services are provided up to 24 hours a day, 365 days a year, during evening, weekend and holiday hours. For some consumers, staff must provide intimate

personal care, and health monitoring in all aspects of daily living. Typically, human services positions do not pay very much, especially the direct service positions. Organizations will need to continue to recognize this problem, and to advocate for funding options to improve staff wages.

Many individuals are interested in living in small settings in the community. It is easy to see why some people would prefer this option. However, there are obstacles to providing these services on a broad scale. Affordable, safe housing is not readily available. In Lawrence, available rental stock is very expensive. The competition for inexpensive housing is incredible, mostly due to the college students' desire for the same opportunities. Also, as consumers move to privately rented locations, vacancies in agency owned or leased properties result. These vacancies cause significant financial difficulties in properties that were built with loans from the U.S. Dept. of Housing and Urban Development. An organization's ability to pay back the loans and related housing expenses solely with tenant-generated income and subsidies is dependent upon full occupancy. When full occupancy is not maintained, the loan obligation must be met with other resources.

Service providers will continue to try to maintain an acceptable balance between promoting and supporting an individual's right to make independent choices, and an organization's responsibility for protecting people from harm. Many of us personally have made informed decisions to pursue courses of action that could have resulted in harm to ourselves. Barring illegal activities, it is our right to do so. However, it is not always clearly the right of our consumers to make choices that are perceived by others to be dangerous. We are required by licensing and by our ethical responsibility to our clients to help them evaluate risks, identify potential negative outcomes, and to possibly take action to prevent harm if the individual is not able to make an informed decision. We are also bound to support a person in a choice that may be contrary to the opinions and wishes of others, if the person is able to make an informed decision. Many of these situations are emotionally

charged and extremely difficult to unravel. Nonetheless, they must occur in order to assist individuals with DD to be as self-directed and empowered as possible.

Current funding levels allow organizations to meet the **needs** of most individuals eligible for and desiring services. However, there is not sufficient funding to meet all of the **wants**. As our service system has grown and become more refined, so have our consumers. We have done an excellent job of informing our consumers of their rights, and of promoting inclusion into their home communities. As a result, consumers are more sophisticated and stronger self-advocates. They want to have many choices in their lives. It is now our task to balance needs versus wants, ensuring that the needs are met for as many people as possible, but also to find ways to assist individuals in obtaining some of the wants too.

Thank you for your time and consideration.



February 5, 1997

Testimony Before the House Committee on Health and Human Services

TO: Representative Carlos Mayans  
House Committee on Health and Human Services

FROM: Steve Gieber, Employment Services Director  
Occupational Center of Central Kansas, Inc.

Thank you Mr. Chairman and House Committee on Health and Human Services I appreciate you allowing me to come and talk to you today.

I'm Steve Gieber from OCKK, Inc. in Salina. I've been working for OCKK, Inc. for the past 18 years. I started as a trainer in a sheltered workshop in Concordia and have been involved in all types of employment services for the past 18 years. I currently am the director of Employment Services for OCKK, Inc. Employment services includes sheltered workshop, enclaves, mobile work crews, supported employment, and supported competitive employment. I have also been the co-convenor of the Interhab Employment Services task force for the past 9 years and currently am serving as a member of the Kansas Rehabilitation Advisory Council. I see the people we provide services to every day.

I would like to give you a brief history of services for people with developmental disabilities in Kansas.

When I was in college at Fort Hays State a friend that I would meet in a few years from then was in Parsons State Hospital for the Mentally Retarded. His name is Don.

When I started at OCCK, Inc. we would look for work to bring into facilities for the consumers to do. Most of the time the work was short in duration with quick turn around times and it was difficult to provide consistent training for individuals to develop good work habits and marketable skills. If you were an individual with developmental disabilities 18 years ago you could choose from a Institution, Sheltered workshop, work activity center, or stay at home.

Don came to this work shop and wanted to learn how to work with metal and weld. Don and I worked on a program to weld for 2 years. I never learned how to teach Don to weld.

13 years ago we began experimenting with taking the consumer to the work and providing the supports in the work place. Some of the things that we began to find was a lot of the jobs that we were finding were more consistent than the ones we were bringing into the facilities. Consumers were learning the task and doing quite well with them. Supports were provided and most sites were still somewhat similar to the workshop but were in the community but not necessarily of the community. Now if you were a person with a developmental disability you had a new choice for work enclaves and mobile work crews.

Don chose to try this and went to work second shift at a plant making the wrist bracelets for hospital at a manufacturing plant in Belleville.

10 years ago we were beginning to experiment with a thing we later would call supported competitive employment. Now we would go out into the competitive job market and try and match jobs to people with disabilities.

Don tried this at a few different locations but it didn't work out very well. It seemed that the jobs we were finding for Don didn't take into consideration his personal needs of family and hobbies.

Refer to 1995 23 Interhab agencies pie charts and graphs

At OCCK, Inc. we serve about 225 people in employment services every day. We have 3 work shops in different communities. We have approximately 100 people in facilities and 125 in various community sites.

At one workshop we package 4 foot florescent lamps for Philips Lighting Corp. 30 people work in that operation. The work is consistent. We currently are packaging a 30 pack that goes to Home Depot. The people really like this work; they find it challenging and fulfilling. This is an example of traditional sheltered employment.

We have an enterpreneuiral Business that we started about 15 years ago where we do janitorial contracts under the name of QCS. We maintain 4 rest areas out on the interstate highway system for KDOT as well as several area businesses like Sears, True Value Hardware, as well as the KDOT district offices. We currently have 25 people who find this work challenging and fulfilling.

We have several people working in plants like Sunflower Mfg. in Beloit and Cawker

City, Great Plains in Abilene and Salina, Love Box company in Salina, M-C Ind. in Belleville. Some of the people work in contracted placements where OCK still issues the person's check.

We have about 40 people who find this type of work challenging and fulfilling.

We have 65 people that we provided supports to in 1996 that have jobs in various communities and businesses in our 9 county area. They are successfully employed in various types of businesses and find their work challenging and fulfilling.

As you can see we use all types of models and will use more as the state of the art for our services continues to evolve. There are some people who claim one type of service is better than another but I believe all of them are needed. My father always told me if you have to put down one religion to make yours look better you may want to take another look at your religion.

We need more options for people with disabilities not fewer. If you have the opportunity to fund more innovative services so we can experiment again I'm sure that we will continue to make progress in our skills and technologies of supporting people with disabilities. We are all experiencing life long learning as our President said in the state of the Union address a few nights ago. When I first started there seemed to be a believe that people with mental retardation stay the same all their life. But now we know that we are all in a world of life long learning.

## THE DIGNITY OF RISK

### What If

you never got to make a mistake...

your money was always kept in an envelope where you couldn't get at it...

you were never given a chance to do well at something...

you were always treated like a child...

your only chance to be with people different from you was with your own family...

the job you did was not useful...

you never got to make a decision...

the only risky thing you could do was act out...

you couldn't go outside because the last time you went it rained...

you took the wrong bus once and now you can't take another one...

you got into trouble and were sent away and you couldn't come back because they always remember you're "trouble"...

you worked and got paid \$.46 an hour...

you had to wear your winter coat when it rained because it was all you had...

you had no privacy...

you could do part of the grocery shopping but weren't allowed to do any because you weren't able to do all of the shopping...

you spent three hours every day just waiting...

you grew old and never knew adulthood...

you never got a chance.

(From a parent whose son is in a supported work program)

Changing Expectations/Planning for the Future: A Parent Advocacy Manual by Dorothy Sauber, published by Association for Retarded Citizens, Minneapolis, MN

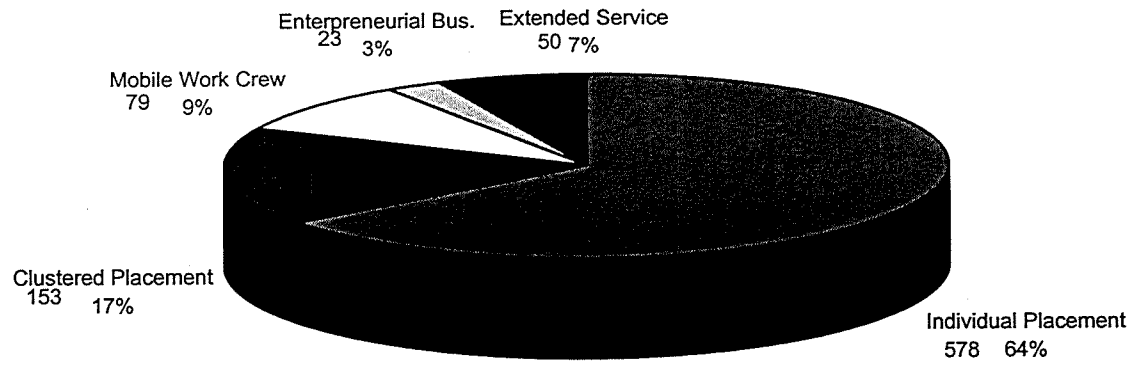
Don continued to take risks and try new things, Don likes to coach Little League baseball in the summer. He attend local sporting events in the evenings. He also likes to see his mom and family on a regular basis. Don currently works at first shift at Sunflower Mfg. in Beloit. He makes the spring assemblies that go on discs. When Sunflower offered Don the job, Don had to take a risk and give up HCBS services, SSDI, Medicare and Medicaid. Don makes \$7.00 an hour works 50 hours a week, has full benefits, including retirement. Don now pays taxes. Don teases his supervisor and co-workers and they tease him. Don likes his job and co-workers and they like him. Don still occasionally needs some supports in his life from us but they become less and less every year.

In order to make all of these options available for people like Don we use all of the following funding sources at different time; HCBS, consolidated funding, Continuation, County Mill levee VR fee for service, VR SESL grants, and discretionary funds.

From the institution to a sheltered workshop to an enclave to various community jobs, to a job earning good money from a tax recipient to a tax payer with a retirement benefit. Don did all of this because he was willing to take a risk. OCCK only created the environment Don made the decisions and did the work to build the life he has. Every ship is safe in the harbor but that's not what ships are built for. Don could have stayed in the institution and been safe but he was willing to take a risk and live life.

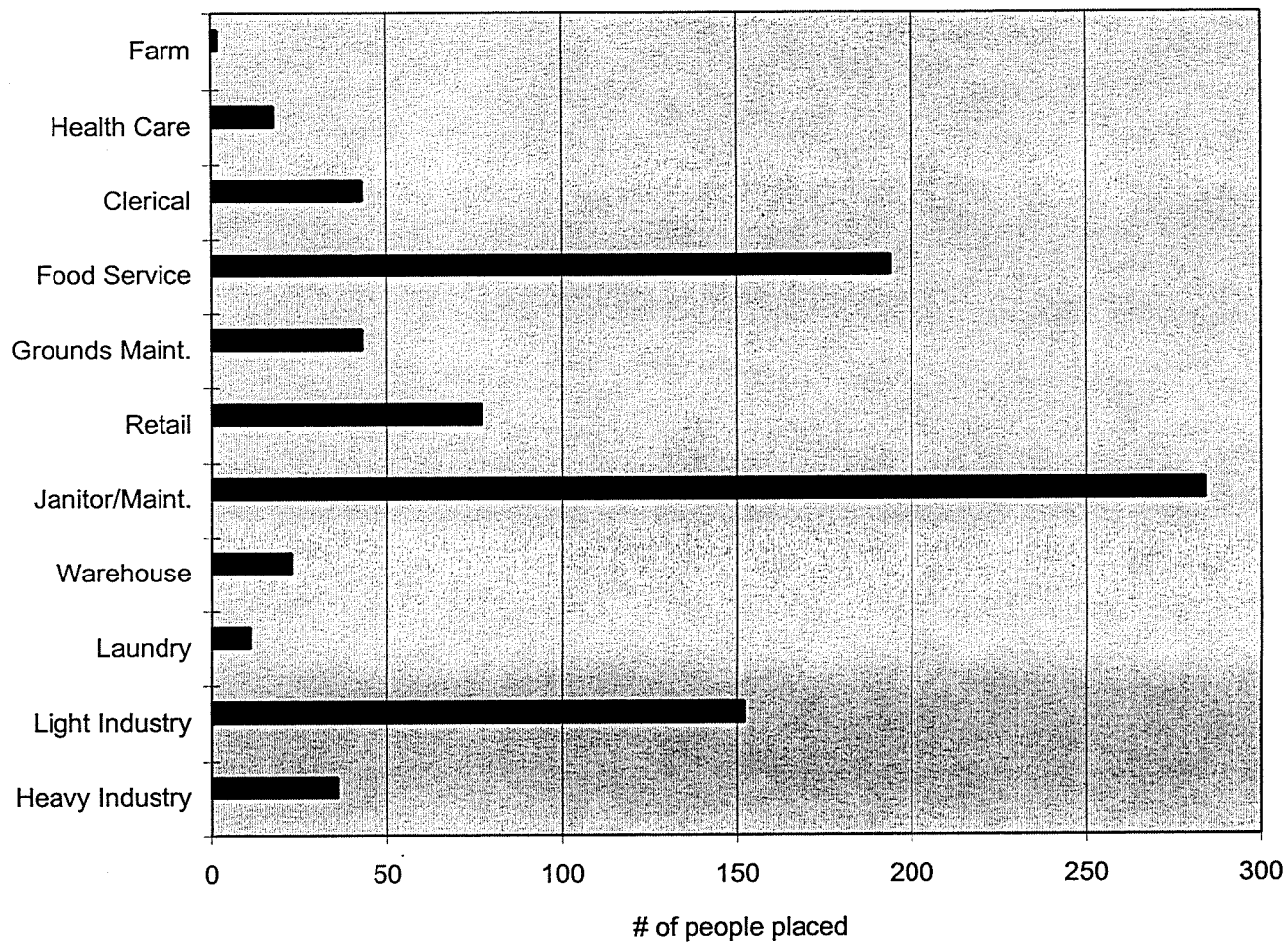
I have told you the story of Don not to show how great Interhab is or OCCK but because of how great I think Don is.

**23 Interhab Agencies**  
**Supported Employment Models providing supports to 883 people with DD**



# 23 Interhab Agencies

Type of Work

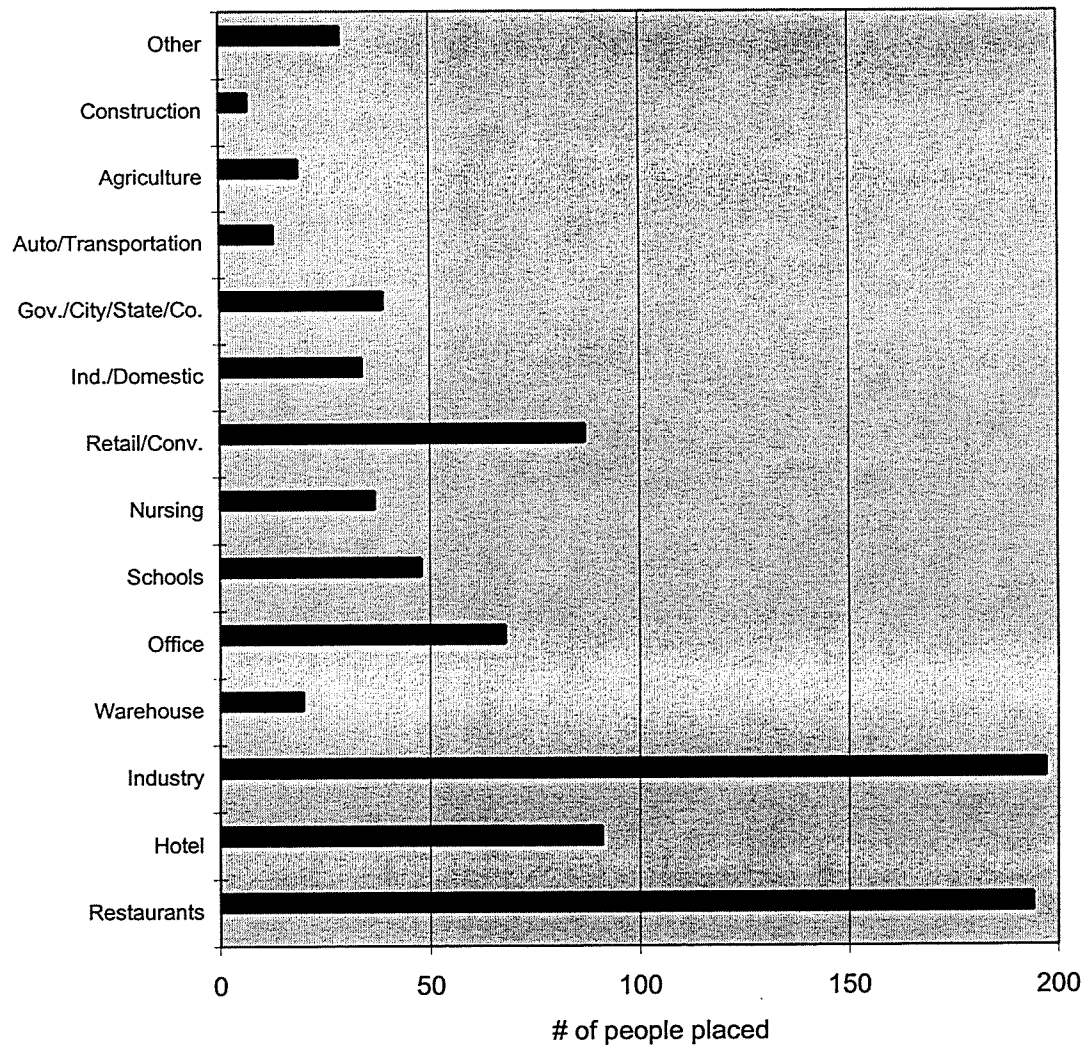


4-8



# 23 Interhab Agencies 1995

## Community Locations



6-7



700 SW Jackson ~ Suite 803 ~ Topeka, Kansas 66603-3758 ~ interhab@ink.org  
voice 913/235-5103 ~ tty 913/235-5190 ~ fax 913/235-0020

## **SUMMARY OF TESTIMONY:**

**Tom Laing, InterHab**

**February 6, 1997**

The Kansas Legislature has played a historically strong role in creating the community systems and supports that are in place today.

With the adoption of the DD Reform Act of 1995, the system of Community Developmental Disability Organizations was strengthened and refined with these principles in mind:

- \* Privatization of state services
- \* Preservation of families
- \* Downsizing state institutional programs
- \* Reduced reliance of individuals for public assistance
- \* Strengthened rights for individuals
- \* Local control of basic system design decision making
- \* Fair business relationships between state and local service organizations

### **Emerging Issues:**

- \* Reform laws to protect vulnerable persons from abuse, neglect and exploitation.
- \* Improve employment programs for persons with disabilities
- \* Improve local service delivery -- in both programmatic and fiscal accountability
- \* Adequately finance the administration of the DD Reform Act as well as the community's efforts to meet individual needs.

### **Summary:**

The Legislature has played a key role in bringing about needed reforms in these programs. We ask them to continue to in that oversight role to assure that community decision making becomes the principle method by which these programs are designed.

## Testimony to the House Committee on Health and Human Services

February 6, 1997

Presented by:

Tom Laing, Executive Director

InterHab: The Resource Network for Kansans with Disabilities

Regarding:

Community Services and Supports for Persons with Disabilities

Representative Mayans and Members of the Committee:

My name is Tom Laing, I am the Executive Director of InterHab: The Resource Network for Kansans with Disabilities. Our membership provides the largest share of all community based services for persons with developmental disabilities available today in Kansas. Among our 48 members are all of the state's 28 locally-designated Community Developmental Disability Organizations, as well as 20 other service providers.

Our members' services range from adult comprehensive services to specialized child care services. Some are very large, both in service population and in the size of their geographic service. Some are very small, such as those who represent the newest trend in service organizations, i.e. organizations who assist families in the recruitment and training of personal in-home attendants for children with disabilities.

On behalf of our members, thank you for arranging these briefings. We appreciate that, amidst the many complex issues facing you, each year the Kansas Legislature deals very seriously with disability related issues. There is no human service field which has received more careful attention in the Legislature, than does the system of community services and supports for persons with disabilities.

### **Historic Development of the System:**

The Legislature has had a major impact in shaping this field in recent years. The original designation of Community Mental Retardation Centers (CMRC's) was a product of legislative initiative in the 60's and has become the network of CDDO's due to the passage of the DD Reform Act of 1995, which is the system we live with today.

Under the provisions of the DD Reform Act, the legislature placed the administrative focus of community services in the hands of local organizations. In so doing, the legislature recognized and codified the trend that emerged over the past thirty years ... i.e. the privatization of services for persons with disabilities.

Prior to the 60's, the only public tax-supported options for persons with disabilities had been large state institutions. Since that time, nearly all growth in services has occurred in the community ... originally, through the expansion of local, large care facilities, and more recently, the predominant growth has been made possible by locally organized private, not-for-profit organizations in smaller, more open and personalized settings.

### **Elements of Today's Community System:**

#### **1. Privatization**

Privatization occurred as it became apparent that the changing patterns of service, the uniqueness of each region or county of the state, and the changing needs of individuals could not all be satisfactorily addressed by a single state approach. The willingness of not-for-profits to initiate leadership in the community made privatization an early and successful option for the state to embrace.

#### **2. Family preservation**

To preserve families was a major reason for promoting the causes of community services. Many, if not most, of the community programs were established by families who, along with their friends and neighbors, wanted their children to have options close to home, where they could retain their natural support network.

#### **3. Downsizing of government programs**

In recent times, as the size of government came under closer scrutiny, the state was able to close institutions first at Norton and now at Winfield only because of the presence of the community network. To then move those tens of millions of service dollars broadly across the state has helped to strengthen the public's understanding and support -- statewide -- for services which were once only available in four Kansas counties, but are now available in all 105 counties. This has made the state budget for these services more meaningful and customer-friendly for all Kansas families who face the unique challenges of disabilities.

#### **4. Reducing reliance on government assistance**

Our programs recognize that for many persons with disabilities, some assistance will always be needed ... assistance that cannot be provided by friends and families. However, we have always operated on the assumption that persons who can support themselves to a greater degree should do so, and we work to empower people to live that philosophy.

Testimony to the House Committee on Health and Human Services  
Tom Laing -- February 6, 1997  
page three

**5. Asserting the rights of individuals, communities and service organizations.**

Kansas law, in the DD Reform Act, provides significant protections against the growth of excessive state governing authority. E.G. ....

A consumer's right to choose among available services is now protected by law, and is only limited by the costs and availability of service choices. Funding rules and state law not only encourages, but enforces, that service organizations must make plans to fit the individual needs of the person who is to receive the services.

**Local authority to select a preferred service coordination approach.** Kansas counties, individually or as multi-county groups, continue to have the right to choose whether county government or a private not-for-profit entity in that region or county delivers needed service coordination in their counties.

**Fair-partnership rules exist for service providers who contract with the state.** The network of county-designated community organizations, as well as their affiliated service providers, have the right to negotiate with the state, and the right to mediation as an alternative to litigation in resolving contract and regulatory disputes.

These innovative approaches are leading us closer to the development of a strong community service system that families can count on, and represent a very positive example of state and local cooperation employed to empower public and private innovation in the community.

**Emerging Issues:**

I would like to highlight a handful of emerging issues upon which you will hear more this year and next, some of which may come before this committee as legislation of other related legislative discussions occur.

### **1. Quality of life for Kansans who have disabilities.**

A prime issue this year will be the reform of the state's laws which are intended to protect dependent persons from abuse, neglect and exploitation (ANE). We are committed to support reforms in that system to assure a safer life for persons with disabilities, to assure that organizations have the resources to hire and train persons who will provide positive care, and to assure that those who commit intentional acts of ANE are screened from the system and not employed elsewhere.

We are working with SRS and the Attorney General's office and a number of other stakeholders to assure also that adequate due process safeguards exist for those who are accused, and have especially stressed the need for an accurate and usable registry of offenders to help community employers keep bad employees from reentering the system.

### **2. Improving the employment status of persons with disabilities**

This is an area for which funding has lagged far behind the needs of the state. Community efforts beginning in 1992 began to secure state funding to support core employment services for persons with disabilities, and those efforts have been successful. But this is a program that falls between the eligibility criteria of state and federal funding sources, and as a result has been left without strong advocates within state government.

We are exploring ways to address that issue this session. Our members feel strongly that the key to securing independence for persons with disabilities is in the employment arena. And while long-term needs of persons may still require funding from the state, those resources are better spent in assisting a person to become less dependent.

Agreements between SRS and the Senate Ways and Means committee last year ended the annual expansion of this program for persons needing long-term supports. We hope to reverse that setback this year.

### **3. Improving local service delivery is of paramount importance to the community providers. Regulations which increase the CDDO role in monitoring affiliated service providers are now in place, but such regulations do not recognize other useful tools in improving program and fiscal accountability, such as national accreditation, which many community providers have undergone voluntarily for many years. Additionally, state budget recommendations for this year have not acknowledged the need for increased training funds to meet the increased training requirements in the community.**

**4. Insuring that legislative expectations are met requires adequate funding.** Funding needs are of an annually recurring nature. The movement of funds from state hospital budgets to the community has meant that those persons will receive most of the services they need.

However, funding concerns remain in these areas:

**1. Minimize the waiting list.**

Last year we moved nearly all state funded service dollars into the Medicaid Home and Community Based Service (HCBS) program and matched (40:60) additional federal dollars. That move reduced the waiting list to the lowest number ever. However, each year, young men and women leave special education and need assistance in the community. If this issue is not addressed annually, the waiting list will grow.

**2. Serve children and families.**

Some children need the variety of services available through Medicaid/HCBS, and increasing numbers of families are using this option. Others may need only occasional services or assistance, and it is in this area where funding lags badly. Additional funding is needed for the family subsidy and support programs, for specialized child care rates for children with disabilities, for respite and assistive technology, and so on.

**3. Finding resources for those who fall between the programs.**

Community organizations historically have served persons with disabilities in need of assistance. However, as the community has supported the state's request to maximize state dollars by matching Medicaid, we have at the same time reduced our funding base which otherwise could serve those who do not meet specific Medicaid eligibility guidelines.

**4. Paying the bills for DD Reform**

The cost estimates associated with the DD Reform Act of 1995 ranged from \$3.8 million to \$7.7 million. No new money was added to the budget for those costs. The response to our concerns last year on this point was the restoration of \$3 million in community support grants which had been cut in the budget recommendations for this year, money which had previously been appropriated as service dollars. We will be asking this year to address this issue. The regulatory scheme adopted to implement DD Reform was not an efficient approach. It must either be financed or reconsidered.

### **Future Challenges:**

It is clear to community providers that modern advances in understanding will continue to require advances in local system designs. Our members have led the forward movement in one paradigm shift after another for the past several years. What needs to be made clear to the state is that its systems, too, must become more flexible and adaptable to the needs of the local community service network, who have the daily face-to-face contact with the persons being served, and therefore have a better understanding for customer preferences.

Programs designed for persons with distinctive and unique needs must be flexible enough to meet those needs. Rules to provide oversight and secure accountability to the community must be flexible to accommodate the fact that all communities are different, and that the citizens of those communities know as well as anyone how to address their needs.

### **Summary:**

Parents, legislators and community leaders have been instrumental in moving this process to where it is today. We would like to be able to say that we can rest easy for a while, but that is not true.

Instead, we will continue to advocate for improvements in the laws and rules that govern the system, and for adequate resources to do those things that we all aspire to do. We will continue to wrestle with state administrators over the regulatory principles that are in place.

And we will continue to ask you to be as involved in monitoring and overseeing the process in the future as you have been to date, to assure that the outcomes envisioned in the DD Reform Act are met.



# ***1997 InterHab Legislative Platform --***

## **I. To enhance the quality of life for Kansans with disabilities.**

A. We urge that consensus be reached with all stakeholders in recognizing that consumers (with advice, as needed, from families, friends and guardians) have the right to choose an affordable lifestyle that meets their personal preferences. We oppose state policies which would override those rights by establishing arbitrary or inflexible living standards beyond that which are required of other Kansans.

B. We urge clear and consistent inter-agency state policies to effectively define and enforce abuse, neglect and exploitation (ANE) laws to assure the protection of dependent Kansans with disabilities. Adequate training and cooperation must be improved between and among state and local entities.

C. We ask that the administration be directed to comply with the statutory requirement to establish a registry of persons who have violated the law, to ensure that community service employers can screen out those persons who have jeopardized the lives, security or dignity of Kansans with disabilities.

## **II. To improve the economic conditions of Kansans with disabilities in the workplace.**

A. We support the expansion of employment programs for persons with disabilities (1) to support and reward efforts of employers who hire persons with disabilities and (2) to maintain a statewide network of employment training and technical assistance resources for persons with disabilities.

B. We encourage the expansion of the vocational rehabilitation programs for supported employment and supported living as have been established by community based service providers, and the joint efforts of state and local leadership to jointly evaluate such programs and establish measurable performance based program standards.

C. We urge the rejection of any employment and training policies which eliminate the availability of long-term supports. The state should not discriminate against persons who want to work but whose disabilities require long term supports.

## **III. To assure that all Kansans benefit from the efficient local delivery of state and federal programs:**

A. We support and encourage outcome-based fiscal and programmatic standards for all organizations which utilize public funds for persons with disabilities.

**III. (Continued)**

B. We urge license-based state recognition of organizations which have voluntarily attained nationally recognized accreditation standards.

C. We support partnership planning between and among state and locally delegated service agencies, public and private, within which local entities have a right to openly and equitably negotiate and mediate issues relating to contracts and rates.

D. We urge that local initiatives of counties and communities be respected in the formulation of state policies, and that the statutory rights of counties not be diminished in any law or policy which addresses local control over the delegation of community service coordination and the public financing thereof.

**IV. To insure that Kansans with disabilities receive supports and services which meet the service expectations articulated by the Governor and the Legislature in policy and law:**

A. We support expanded funding for Family Support services to aid the efforts of families of persons with disabilities. Additional funding is needed (1) to expand the number of families receiving Family Subsidy, (2) to assure adequate rates for foster care and child care services for children with special needs, and (3) to expand the availability of respite care and supportive home care services to enable children to remain in their homes.

B. We support expanded base-funding for local program coordination and for the effective delivery of government sponsored programs administered by the community service network, and that the allocation of such funding within the SRS/MHDDS budget continue to reflect the statutorily required shift from institutional to community-based services.

C. We support policies that maximize the receipt of available federal assistance, and urge that efforts be made to expand state match dollars for HCBS funding for children.

D. We support the development of annual consensus estimates -- formulated by state officials (executive and legislative) and community service providers -- to provide information on the unmet service needs of Kansans with disabilities, including:

- (1) those currently ineligible for state or federal funding, and
- (2) eligible persons for whom insufficient funding exists.

Only through full disclosure of unmet needs can the Legislature gain accurate information from which to consider "safety net" funding for persons with disabilities who "fall between the cracks" of arbitrary state and federal funding guidelines.