

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 January 23, 1995 in Room 521-S of the Capitol.

All members were present except: Representative Carlos Mayans. Excused

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

Conferees appearing before the committee:

Jane Rhys, Exec. Dir., Ks. Developmental Disabilities Council
Sharon Huffman, Ks. Commission on Disability Concerns
Bob Geers, Administrative Coordinator, The ARC of KS
Gina McDonald, Ks. Assn. of Independent Living Centers
Shannon Jones, Exec. Dir. Statewide Independent Living Council of KS

Others attending: See attached list

Conferees were present to provide committee members information regarding each groups' present function and future goals. Jane Rhys, Executive Director of Kansas Developmental Disabilities Council (Attachment 1). Ms Rhys summarized the Council's three most important goals: 1. Need a strong message from the Legislature that people are going to be moved into the community; i.e. a policy statement. Ms. Rhys promised to provide the committee possible language for such a statement. 2. To further support this policy, need more funds or at least a realignment of existing funds to support CMRCs, and or other community resources, decrease the waiting lists, and care for additional customers entering the system each year. 3. Increase users independence and cease "over serving" customers; i.e., stop deciding every facet of their lives.

Sharon Huffman, Kansas Commission on Disability Concerns (Attachment 2). This Commission's current chief goal is to develop a statewide resource directory.

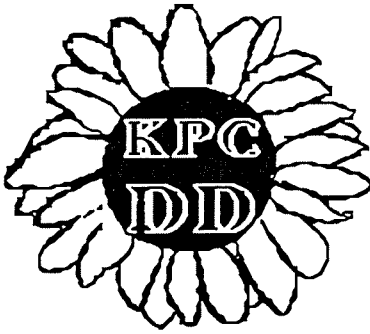
Bob Geers, Administrative Coordinator, The ARC of Kansas (Attachment 3). ARC's main goals are: 1. To redirect funds to community based programs where the dollars can go much further and enable the developmentally disabled to become more independent and participate as equal citizens. Mr. Geers' described the progress made by his son Ben who was a PKU baby, born before new born testing was done in the State of Kansas. Mr. Geers' opinion is that if the dollars are available, services will be there to meet the needs. He believes the current system for insuring quality of service works quite well.

Gina McDonald, Executive Director for the Kansas Association of Independent Living Centers (Attachment 4). The Centers also look forward to funding streams and policies to support more independence, to provide services in "natural" settings etc. The Medicaid buy in idea perhaps again should be considered for the medically underserved living in the Centers. A simple solution to problems created by guardianships would be for the state to issue guidelines stating that admissions to state hospital are no longer an option except under certain specific extreme conditions. Regulations are needed to initiate changes in attitudes, to further increased independence for the developmentally disabled and promote the idea that the "key" to progress is consumer control.

Shannon M. Jones, Executive Director, Statewide Independent Living Council of Kansas (Attachment 5). SILCK's would like state policy to include CIL's as a choice, thereby providing another option to reduce waiting lists for services.

The next meeting will be Wednesday, January 25 in Room 522-S at 3:30 p.m.

The meeting adjourned at 5:00 p.m.



Kansas Council on Developmental Disabilities

BILL GRAVES, Governor
WENDELL LEWIS, Chairperson
JANE RHYS, Executive Director

Docking State Off. Bldg., Room 141, 915 Harrison
Topeka, KS 66612-1570
Phone (913) 296-2608, FAX (913) 296-2861

"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES

JANUARY 23, 1995

To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities.

Madame Chairwoman, Members of the Committee, I am appearing today on behalf of the Kansas Council on Developmental Disabilities to tell you of our dream for Kansas.

The Kansas Council is a federally mandated, federally funded council composed of individuals who are appointed by the Governor. At least half of the membership is composed of individuals who are persons with developmental disabilities or their immediate relatives. The major state agencies who provide services for individuals with developmental disabilities are also represented. I have provided you with the definition of developmental disabilities from Public Law 103-230, the Developmental Disabilities Assistance and Bill of Rights Act of 1994, under which we operate. Under the Developmental Disabilities Act, Section 121, our role is to "promote, thorough systemic change, capacity building and advocacy activities that are consistent with the policy under section 101(c)(2), the development of a consumer and family-centered, comprehensive system and a coordinated array of culturally competent services, supports, and other assistance designed to achieve independence, productivity, and integration into the community for individuals with developmental disabilities."

We believe that individuals with developmental disabilities, no matter how severe the disability, have the ability, and even the *right* to make informed decisions, to have choices about where they wish to live, work, what leisure activities they wish to participate in and so forth. Our dream is to turn that belief into reality. To do this we must decrease the waiting list of individuals who want services in the community by increasing the number of services available. This will require either new funds or the redirection of funds, currently supporting state hospitals, into community services.

*House SC on Developmental
Disabilities 1-23-95
Attachment 1*

Individuals with developmental disabilities have been segregated because of their disabilities, much like individuals who come from different ethnic and racial backgrounds. We have paid for large state run institutions for the developmentally disabled for many years because we believed that separate but equal facilities were “good” for them, because we felt that they were not capable of making decisions. We have learned much more about these individuals: they are capable of making decisions regarding where they want to live; what job they wish to do; what they want to eat, to wear; who they want as friends; what leisure activities they wish to pursue; in short, most of them can make these decisions just as you and I do. Our dream for the future would be that individuals with developmental disabilities are empowered to make these decisions; to achieve independence, productivity, and integration into the community.

Jane Rhys, Executive Director
Kansas Council on Developmental Disabilities
Docking State Office Building, Room 141
915 SW Harrison
Topeka, KS 66612-1570
913 296-2608

The Kansas Council on Developmental Disabilities

A Vision for Kansas

(1) **In General:** The DD Act values personal and family responsibility. The Kansas Developmental Disabilities Council has shown that with supports people with developmental disabilities can attain independence. Removal of supports almost guarantees dependence and reliance on expensive and inappropriate services.

Since 1971 the Kansas Developmental Disabilities Council has assisted people with developmental disabilities to obtain the supports they need in their communities. We cannot eliminate or water down programs that provide cost-effective supports, instead we must expand such programs to provide these individuals the opportunity of choice in where they live, work and do leisure activities. Losing such supports could force people with developmental disabilities into expensive and inappropriate forms of institutional care.

(2) **About Adults:** Adults with developmental disabilities want to make their own choices, live independently, and have real jobs. They do not want to be dependent upon "service systems" or their aging parents. Many adults with developmental disabilities have been shut out of employment opportunities. To attain self-sufficiency, self-determination and independence in living and working, they need specialized supports. They cannot do it alone.

Essential goals of the Kansas Council on Developmental Disabilities are independence - making choices that affect one's own life - and productivity - engaging in income producing work that increases income, improves employment status and job advancement and contributes to one's own household, family, community, state and nation. The Council, with its limited resources and many years of experience, has shown that this can be done. We have led the way in the creation of employment support programs and are currently planning a conference for employers to provide them with knowledge on employing individuals with developmental disabilities.

(3) **About Children and Families:** Families have always provided the basic support for people with developmental disabilities, particularly children. Families do not want professionals to interfere in family life nor do they want to be "over served," that is, to accept more services than they really need simply because those services are what the providers offer. Rather, they want support in educating and obtaining specialized services and supports for their sons and daughters, to be the best parents they can be. Families cannot do it alone.

A guiding principal for the Kansas Developmental Disabilities Council is the primacy of the family as decision-maker, as expert, and the legitimacy of receiving publicly-funded supports they cannot provide on their own. The Kansas Council has created family supports, such as the Parent-To-Parent project, that have proved to be cost effective: they prevent expensive, unnecessary, wrenching and inappropriate out of home care, and strengthen and maintain the family unit.

(4) **About Communities:** The community is where the majority of people with developmental disabilities want to live. Communities provide many informal supports - at home, at school, in neighborhoods, through local associations and organizations. These should be encouraged. People with severe life-long disabilities require a federal role in the provision and monitoring of services, supports and in civil rights protections. Informal supports alone are not enough to ensure that people with developmental disabilities become taxpayers and are protected from harm.

The Kansas Developmental Disabilities Council has made major investments in communities, to enable them to include and embrace people with developmental disabilities. We recognize that we are all

interdependent - people need each other. The Council nurtures supportive communities and help the general public to offer opportunities to people with developmental disabilities. The Council works to ensure that necessary services exists which cannot be provided informally.

(5) About People with Developmental Disabilities As Citizens: The Kansas Developmental Disabilities Council helps citizens with developmental disabilities and their families to learn to govern themselves, direct their own futures and exercise an essential function in democracy. A majority of the Council is comprised of these citizens and it is they, in consultation with public and private providers, who make the decisions about how to invest Council funds. They support new ideas, demonstrate what works best for them, and take responsibility for their own futures. They tell the state and private providers what is needed and what works and how to fix what doesn't work.

The Kansas Developmental Disabilities Council is truly customer-directed and controlled by those who use the services system. We are a training ground for people with developmental disabilities and parents to speak for themselves and to influence public policy.

(6) About the State: The Developmental Disabilities State Grant Program is a state-operated program, responsive to the needs of the states and localities and THE PEOPLE it is designed to assist. The state plan developed by the Developmental Disabilities Council is unlike other state plans for services: it is a blueprint or road-map, for improving the system of services, containing strategies for investing in innovation, cost-effective approaches to services and supports, and empowering people to advocate for themselves. The Council is mandated to improve generic programs to serve people with developmental disabilities and significant progress has been made in recent years. The Council consists of state government officials and people with developmental disabilities and family members, the key stake holders who provide and use services. Together, these Governor appointed Council members design approaches for making the system work better, smarter and more cost-effectively. We conduct policy research to give Governors and legislatures the information they need to make good disability policy decisions. Our funding flexibility enables them to demonstrate to policy makers what works and how to make it easier for people to navigate complicated bureaucracies.

The Kansas Developmental Disabilities Council uses their expertise and experience to work with the Governor and state legislators as well as the private sector to design, re-design and fund creative and cost-effective solutions at the state level, leveraging other public and private funds and activities. The Council has fostered some of the field's most innovative ideas: supported work, supported living, and family support - all designed to lessen reliance on expensive institutional, caretaking models which fund care-giving industries rather than people.



Kansas Department of Human Resources

VOICE
(913) 296-1722
TTY
(913) 296-5044
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(913) 296-1984

COMMISSION ON DISABILITY CONCERNS
1430 S.W. Topeka Boulevard
Topeka, Kansas 66612-1877

TOLL FREE
OUTSIDE TOPEKA
1-800-295-5232 (KCDC)
ADA INFORMATION
CENTER (BBS)
(913) 296-6529

**Testimony Presented to
Select Committee on Developmental Disabilities
January 23, 1995**

by

**Sharon Huffman
Legislative Liaison**

Madam Chair and members of the Committee, thank you for this opportunity to speak before you today regarding the gaps in the state's handling of developmental disabilities.

The Kansas Commission on Disability Concerns (KCDC) believes that all people with disabilities are entitled to be equal citizens and equal partners in Kansas society. The purpose of KCDC is to involve all segments of the Kansas Community through legislative advocacy, education and resource networking to ensure full and equal citizenship for all Kansans with disabilities.

Our office functions as a resource for individuals seeking information about a variety of disability-related issues. We receive numerous phone calls each day from private citizens, employers, businesses and representatives of state and local government inquiring about their rights or responsibilities under the Americans With Disabilities Act and other disability rights laws. Many of the individuals who call are looking for resources within their community for themselves or a family member.

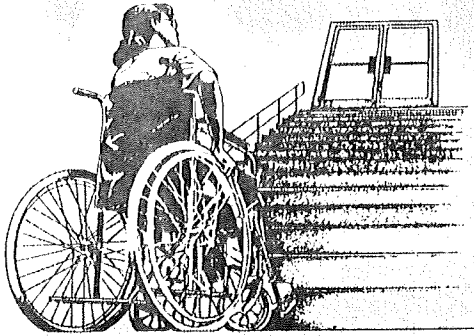
Currently there is not a single resource directory that lists all the various resources available within the state that provide services for people with disabilities. It is a dream of KCDC to compile such a directory that can be made available statewide.

*House SC on Developmental
Disabilities 1-23-95
Attachment 2*

It is my understanding that this committee is interested in finding out what is needed to help close the gaps in community-based services to people with developmental disabilities. All the services in the world won't help unless the person needing those services is aware of their existence. KCDC would like to work with this committee, as well as our fellow advocates throughout the state to develop a resource directory for community-based services for Kansans with disabilities.

Thank you again for this opportunity to participate today.

KCDC believes that all people with disabilities are entitled to be equal citizens and equal partners in Kansas society. The purpose of KCDC is to involve all segments of the Kansas Community through legislative advocacy, education and resource networking to ensure full and equal citizenship for all Kansans with disabilities.



For more information about the Commission, please contact us at:

Commission on Disability Concerns
Kansas Dept of Human Resources
1430 SW Topeka Boulevard
Topeka, Kansas 66612-1877

Voice (913) 296-1722

TTY (913) 296-5044

Fax (913) 296-1984

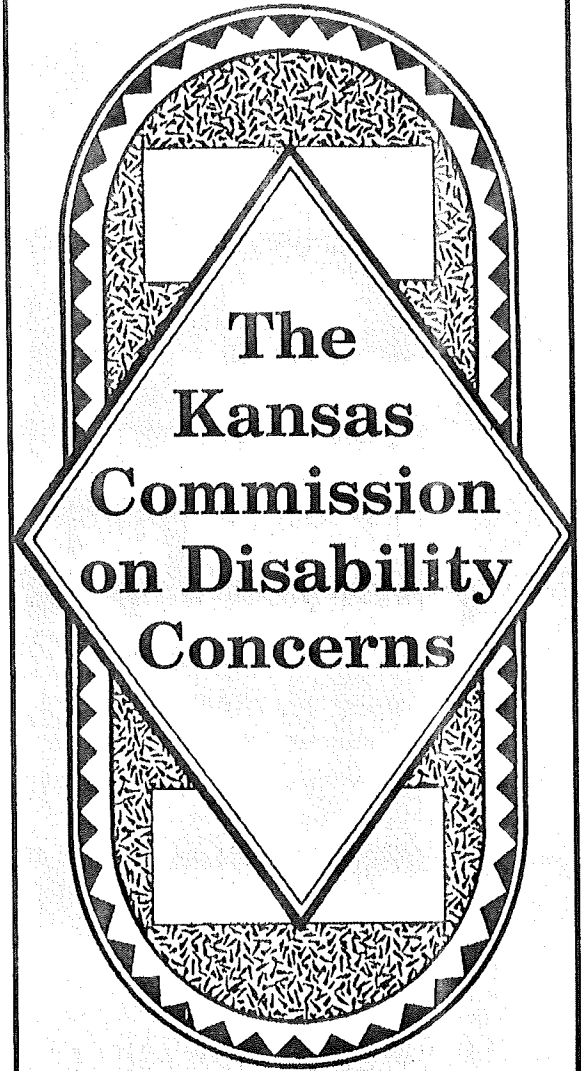
BBS (913) 296-6529

Toll Free (Outside Topeka) - 1-800-295-5232

K-CDC 106 (Rev. 5-94)



COMMISSION ON DISABILITY CONCERNS
KANSAS DEPT OF HUMAN RESOURCES
1430 SW TOPEKA BLVD
TOPEKA KS 66612-1877



Kansas Department
of Human Resources

The Commission promotes the integration of people with disabilities into society by providing the following services:

- **Training** . . . on the legislative process, disability civil rights, legal requirements, disability awareness, accessibility, and legal remedies.
- **Technical Assistance** . . . with accessibility reviews, fundamentals of organizing disability groups, legislative commentary, policy consultation, development of employment and training programs, and research and analysis of disability issues.
- **Information and Referral** . . . on complaint processing, employment incentives, available products for people with disabilities, supervision of disabled workers, legislative testimony, job placement, service delivery, disability organizations, and job vacancies.

The Commission provides these services to employers, disability organizations, state and federal agencies, the governor's office, U.S. congressional representatives and senators, the state legislature, civic organizations, professional groups, and people with disabilities.

The Commission, as established by law, is empowered to:

- Carry on a continuing program to promote a higher quality of life for people with disabilities;
- Cooperate with all public and private agencies interested in promoting independent living by people with disabilities;
- Cooperate with all agencies responsible for or interested in the rehabilitation and employment of people with disabilities;
- Encourage the organization of community-based programs and work closely with such programs in promoting independence of people with disabilities;
- Assist in developing societal acceptance of people with disabilities;
- Inform individuals with disabilities of specific facilities available for increasing their independence;
- Conduct such educational programs as members deem necessary; and
- Report annually to the governor and legislature on commission activities and submit any recommendations believed necessary to promote the independence of people with disabilities.

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ADA Information Center B.B.S.

(913) 296-6529

Information & Fact Sheet

This electronic bulletin board service was established to provide everyone access to **AMERICANS WITH DISABILITIES ACT (ADA)** information via the use of a personal computer and computer modem device.

- * We are offering the latest ADA information from many sources throughout the United States. A one stop shop to receive any needed information of this type.
- * ADA-Net International Net-Mail Service On-Line with over 100 different message conference areas of information for and/or about disability and medical information from all over the U.S.
- * Misc. files also available about Rehab Act, Social Security Information, with U.S. Codes related to all the above listed.

On-Line 24 hours a day using Mustang Bulletin Board Software, Hayes 28,800 modem for the fastest file transfers possible. In house ADA specialist to answer your ADA questions and concerns.

George Wolf/Sysop	(913) 296-6528 - Voice
Alan Schlobohm/Co-Sysop	(913) 296-1984 - Fax
	(913) 296-5044 - TTY

KS. Commission on Disability Concerns
(913) 296-1722 outside Topeka (800) 295-5232
Voice & TTY

public.

Moderator: Andrew Walding

3. RESUMES-Technical/
Engineering Net users can post their ASCII resumes for capture and review by potential employers. This conference will be classified as Technical and Engineering resumes.

Moderator: OPEN

4. RESUMES-Clerical/
Administrative Net users can post their ASCII resumes for capture and review by potential employers. This conference will be classified as Clerical and Administrative resumes.

Moderator: .OPEN

5. RESUMES-Professional
and Managerial Net users can post their ASCII resumes for capture and review by potential employers. This conference will be classified as Professional and Managerial resumes.

Moderator: OPEN

6. RESUMES-Miscellaneous Net users can post their ASCII resumes for capture and review by potential employers. This conference will be classified as Miscellaneous resumes.

Moderator: OPEN

7. JOB SEEKING The focus of this conference is where, how, and advice on job hunting. Stories on how you fared on your last or present job search are welcomed.

Moderator: OPEN

8. INTERVIEWING An open forum discussion that can benefit job seekers as well as hiring managers. The focus here is on the interview: the good, the bad, and the ugly! We want stories, advice, and experiences discussed here!

Moderator: OPEN

9. JOB AND CAREER FAIRS Nationwide career and job fair information can be found here. We look for job seekers and employers to place informational posting here.

Moderator: OPEN

10. CLASSIFIED-Accounting
& Financial Positions

Job Seekers and Hiring Employers should post their current positions in the categories of Accounting and Financial positions jobs in this conference.

Moderator: OPEN

11. CLASSIFIED-Chemical
Engineering

Job Seekers and Hiring Employers should post their current positions in the category of chemical engineering jobs in this conference.

Moderator: OPEN

12. CLASSIFIED-Technical
Non-Classified

Job Seekers and Hiring Employers should post their current positions in the categories of technical and engineering jobs that are not specifically classified to any other JobNet technical classified conferences in this conference.

Moderator: OPEN

13. CLASSIFIED-Clerical/
Administrative

Job Seekers and Hiring Employers should post their current positions in the categories of clerical and administrative jobs in this conference.

Moderator: OPEN

14. CLASSIFIED-Professional
and Managerial

Job Seekers and Hiring Employers should post their current positions in the categories of professional and managerial jobs in this conference.

Moderator: OPEN

15. CLASSIFIED-Contract
TEMP Positions

Job Seekers and Hiring Employers should post their current positions in the categories of Contract and TEMPorary jobs in this conference.

Moderator: OPEN

16. CLASSIFIED-DP/MIS &
Software Related

Job Seekers and Hiring Employers should post their current positions in the categories of DP/MIS and software related jobs in this conference.

Moderator: OPEN

17. CLASSIFIED-Electrical

Job Seekers and Hiring Employers should

- & Electronic Engrng. post their current positions in the categories of Electrical and Electronic Engineering jobs in this conference.
- Moderator: OPEN
18. CLASSIFIED-Environmental Engineering Job Seekers and Hiring Employers should post their current positions in the categories of Environmental Engineering jobs in this conference.
- Moderator: OPEN
19. CLASSIFIED-Misc. Job Seekers and Hiring Employers should post their current positions in the miscellaneous category in this conference.
- Moderator: OPEN
20. CLASSIFIED-International Job Seekers and Hiring Employers should post their current positions in the international marketplace in this conference. There is no classification restriction, just international!
- Moderator: OPEN
21. CLASSIFIED-Multiple Job Listings Job Seekers and Hiring Employers should post their multiple job listings in this conference. This is handy for large hiring efforts and large corporations. There is no specific job type here as many types can be contained within the multiple listing.
- Moderator: OPEN
22. CLASSIFIED-Health & Medical Related Job Seekers and Hiring Employers should post their current positions in the categories of Health and Medical related field jobs in this conference.
- Moderator: OPEN
23. CLASSIFIED-Human Resources, Personnel Job Seekers and Hiring Employers should post their current positions in the categories of Human Resources, Personnel and related fields jobs in this conference.
- Moderator: OPEN
24. CLASSIFIED-Mechanical Engineering Job Seekers and Hiring Employers should post their current positions in the categories of Mechanical Engineering jobs in this conference.

Moderator: OPEN

25. CLASSIFIED-Miscellan.
Engineering

Job Seekers and Hiring Employers should post their current positions in the categories of Micellaneous Engineering jobs in this conference.

Moderator: OPEN

26. CLASSIFIED-Local
Positions

Job Seekers and Hiring Employers should post their current positions that are only to be advertised in the STATE in which the BBS which carries JobNet operates. Each JobNet BBS will take care to echo this conference only within the state in which it operates.

Moderator: OPEN

27. CLASSIFIED-Purchasing
Buying/Contracts

Job Seekers and Hiring Employers should post their current positions in the categories of Purchasing, Buying, and contracts related jobs in this conference.

Moderator: OPEN

28. CLASSIFIED-Sales &
Marketing

Job Seekers and Hiring Employers should post their current positions in the categories of Sales and Marketing jobs in this conference.

Moderator: OPEN

29. CLASSIFIED-Technical
Writing and Related

Job Seekers and Hiring Employers should post their current positions in the categories of technical writing and related jobs in this conference.

Moderator: OPEN

30. FAIRNESS IN EMPLOYMENT

So many complaints and stories about fairness in employment practices involving race, religion, and age discrimination that we have dedicated a conference solely to this topic. Debate, discussion, and stories are welcomed here from both hiring employers and job seekers.

Moderator: OPEN

31. WRITING YOUR RESUME

An area where all of us can get advice, share success stories as well as lessons learned from writing/creating resumes. Follow the

The Following Conferences Will Be Available On
ADA Information Center B.B.S. Via ADANet Coming
April 1, 1994

These conferences originate in ADANet. They have a narrow focus relating to disability.

ACCOMMODATION	Job Accommodation Information
ADACHILD	Disabled Children - A place for help
ADAJOBS	International Employment for Disabled
ADANET	ADANet International Topics Forum
ADAPTIVE	Adaptive Technology Discussion
ADARIGHTS	Disability Rights and Political Forum
ADASY SOP	A forum for ADANet SysOps onyl...
ADATECH	ADANet Technical Forum (Private Conf)
ADA_FAMILY	Disability and the Family Discussions
ADA_OCCUPATION	Occupational Disabilities Discussion
ADA_OUTDOORS	Disabled Outdoors Conference
ADA_SEXUALITY	Disability and Sexuality Discussion
ADVOCACY	Advocacy for Disability Issues
ALLERGIES	Conference on Allergies
ARTHRITIS	Arthritis Discussion Group
ASL	American Sign Language Conference
ASSIST_4SALE	Assistive Technology For Sale Area
BARRIERS	Architectural Barriers Conference
BURN	Disability and Burn Discussion
CARDIAC	Cardiac Care and Support Echo
CROSS	Cross Disability Awareness Committee
CTS	Carpel Tunnel Syndrome Support Group
DESHABILITADO	Disability Discussion in Spanish
DIALYSIS	Conference on Dialysis / Renal Disease
DIGEST	Handicap Digest Issues and Indices
DWARFISM	Dwarfism Conference
EDUTEL	Special Education Conference
FRANCO_HANDICAP	Disabilities Support Echo in French
GOLDEN_YEARS	Elderly and Geriatric Issues
HANDILAW	General Discussion on Disability Law
INDEP	Discussions on Independent Living
LEARNING	Online Learning and Disability
MEDICAL	General Medical Information Echo
MEDICATION	Disability and Medications
MOBILITY	Mobility-impairment and coping
MUSCULAR_DYST	Muscular Dystrophy Conference
OCC_INJURY	Topics regarding Occupational Injury
PHILO	The Philosophy of Disability Issues
README.ADA	Beginner's Help Corner
RESPIRATORY	Respiratory Disease Discussion/Therapy
RETARDATION	Discussion of Retardation
SILENT_CRY	Emotional, Physical and Sexual Abuse
TECH_ACT	Conference for the Tech Act States
WAN_DBASE	Development of Wide-area net database
ABLE.EUR	disABILITY Echo from Europe
ABLED_ART	Literature and Art by and for PwD's
ALTLEARN	Alternative Learning Discussion

ALZHEIMERS	Alzheimer's Discussion Forum
BICOMPAL	Big Computer Pals (UUCP)
BLINDTLK	BlindTalk from Nat'l Fed. of Blind
BRIDGES	Chat with disabled children conference
DATATALK	Adaptive Computing for the Disabled
DISABLED_VET	A conference for disabled veterans
ENABLE	Inter-network disability conference
EPILEPSY	Epilepsy management and coping
HOLISTIC	Holistic Thinking and Healing
NFB-TALK	Nat'l Fed of Blind Friends/Fellowship
PSYCH	Psychology Discussion and Issues
SPECIAL_ED	Special Education Conference
TCM	Traditional Chinese Medicine
TERM_ILL	Discussions regarding Terminal Illness
VHEAL	Vibrational Healing Conference
ABLED	General Disability Discussions
ABLED_ATHLETE	For Disabled Athletes
ABLENEWS	Disability News / Articles & Releases
ADHD	Attention Deficit and Hyperactivity
AIDS/ARC	Support and Information for AIDS/ARC
AMPUTEE	Amputee Discussions and Conversation
ANXIETY	Anxiety Disorder Discussion
ASK_A_NURSE	Ask a nurse - Nursing and Healthcare
BATTERED	Family Violence Support Echo
BLINKTALK	Visual Impairment Issues and Discussion
BODYWORK	Massage and Bodywork Forum
CARCINOMA	Cancer and related disease conference
CARE_GIVER	Care Giving and Personal Care Attendant
CFS	Chronic Fatigue Syndrome Conference
CHRONIC_PAIN	Pain management and coping conference
CPALSY	Cerebral Palsy Support Echo
CUSS	Computer Users in the Social Sciences
DIABETES	Diabetes Treatment and Management
DIETING	DiETING Conference and Support
FIRENET	Emergency Medicine and Rescue
HANDY.SYSOP	For SysOps interested in disability
HOME_OFFICE	Techniques/Support in Home-Office Mgt.
MENTAL_HEALTH	Discussions on Mental Health issues
MULT-SCLEROSIS	Multiple Sclerosis Discussions
M_P_D	Multiple Personality Disorders
NURSES_NETWORK	Discussion group just for Nurses
OPTOMETRY	Optometry Discussions and Issues
POST_POLIO	National Post Polio Survivors Forum
PROBLEM_CHILD	Behavior modification and children
PUBLIC_PSYCH	Public Psychology and Discussion Issues
RARE_CONDITION	Rare Diseases and their Discussion
RECOVERY	Recovery Echo
SILENTTALK	Conference for Hearing-Impaired People
SIP_AA	Alcoholics Anonymous Conference
SIP_NA	Narcotics Anonymous Discussion Group
SPINAL_INJURY	Discussions about Spinal Cord Injury
STRESS_MGMT	Stress Management Echo
SURVIVOR	Conference for Survivors
THI_CVA	Discussions of Brain Injury
WELFARE	Discussion on Welfare



The Arc of Kansas

3601 S.W. 29th, Suite 237
Topeka, Kansas 66614
913-271-8783

January 23, 1995

TO: Rep. Pottorff, Chair.
Members of the House Select Committee on Developmental
Disabilities

FROM: Bob Geers, Coordinator

RE: Overview of The Arc of Kansas (formerly The Kansas Association
for Retarded Citizens)

The Arc of Kansas is marking its 38th year of service to people with mental retardation. The 5,000 members of The Arc of Kansas, together with the more than 1,200 other state and local chapters of The Arc throughout the country, form the largest voluntary organization in the United States devoted solely to the welfare of the more than seven million people with mental retardation and their families and to the prevention of this condition for future generations.

In the United States there are an estimated 1.5 million children and adults who, as a result of mental retardation, with or without concurrent disabilities, require ongoing supportive services, whether of a limited, extensive or pervasive character. In addition at least as many as five million more people may be identified, at some point in their lives, as having mental retardation. The Arc is also concerned about the welfare of those individuals who are not labeled as having mental retardation but whose functional skills are such that they will need at least intermittent support services in order to live the productive and participatory lives of which they are potentially capable.

The Arc is an open membership organization that welcomes family members, friends, interested citizens, and individuals with professional interest in the field, as well as people who seek to speak for themselves despite their cognitive impairments.

Members work in their respective communities for access to improved services, wider social participation, and enhanced opportunities for the attainment of self-selected goals by people with mental retardation and their families. We share these objectives with citizens with other disabilities.

formerly the Association for Retarded Citizens of Kansas

*House SC on Developmental
Disabilities 1-23-95
Attachment 3*

The following is the mission statement of The Arc of Kansas.

"The Arc of Kansas is committed to securing for all people with mental retardation and other developmental disabilities the opportunity to choose and realize their goals of where and how they learn, live, work and play."

"The Arc of Kansas is further committed to reducing the incidence and limiting the consequence of mental retardation and other developmental disabilities through education, research, advocacy and the support of families, friends and community."

"Through the successful pursuit of quality and justice, The Arc of Kansas will provide leadership in the field of mental retardation and other developmental disabilities."

The Arc of Kansas urges that the first priority of the Kansas Legislature be to fully fund the community-based consumer directed services that provide outcomes which insure that people with disabilities have the opportunity to participate as equal citizens

PERSONAL STATEMENT

As a parent I would like to take this opportunity to personally thank the Legislature and others who have been responsible for the significant improvements in the quality of life for my son during the past several years. Fourteen years ago I was very fortunate to have Ben accepted into a very crowded (12 persons) group home. It certainly was not ideal but it was a start toward independence. After several moves, today, Ben is extremely happy with a great deal of independence while sharing an apartment with another developmentally disabled individual.

Although Ben continues to face many obstacles and barriers on a daily basis, there are many others like Ben who have not begun to realize how much they can accomplish in a least restrictive environment. I am certain that this can only begin to take place when dollars are redirected from institutional settings and are earmarked to follow the individual into community-based programs.



Gina McDonald
Executive Director

Member Agencies:

ILC of
Southcentral Kansas
Wichita, KS
316/838-3500 Voice/TT

Testimony to
House Select Committee on Developmental Disabilities
Representative Jo Ann Pottorff, Committee Chair

Submitted by Kansas Association of Centers for Independent Living
January 22, 1995

Independence, Inc.
Lawrence, KS
913/841-0333 Voice
913/841-1046 TT

Thank you for the opportunity to discuss possible future options for people who have developmental disabilities. My name is Gina McDonald and I am the Executive Director for the Kansas Association of Centers for Independent Living (KACIL). Centers for Independent Living are advocacy organizations that work to ensure independent living is an option for all people with disabilities. We do this by working to impact laws, as well as providing services in order for them to have choices.

Independent Connection
Salina, KS
913/827-9383 Voice/TT

LINK, Inc.
Hays, KS
913/625-6942 Voice/TT

We are consumer directed organizations, which means that a majority of the boards and staff of a CIL must be people with disabilities. We believe that with supports, anyone can live independently, and that these supports should be determined and controlled by individuals and /or their family/friends. For us, independently living is not doing everything for ourselves, but it is being in control of the available options.

The WHOLE PERSON, Inc.
Kansas City, MO
816/561-0304 Voice
816/531-7749 TT

There are nine CIL's represented by KACIL. About ??? percent of the people who receive assistance from these CIL's are people with developmental disabilities. That number continues to grow each year as people with developmental disabilities and their families learn who we are and what we do. We work very closely with Families Together, Inc.

Topeka Independent Living Resource Center
Topeka, KS
913/233-4572 V/TT

Southeast Kansas Independent Living, Inc.
Parsons, KS
316/421-5502 Voice
316/421-6551 TT

I, as well as many of the staff of CIL's in Kansas have extensive experience working in agencies that serve people with developmental disabilities. I continue to provide training to staff at CMRC's and CIL's in Kansas and around the nation. Through these experiences, we have learned a great deal about gaps in community based services.

Accessing Southwest Kansas (ASK), Inc.
Dodge City, KS
316/225-6070 Voice/TT
1-800/871-0297

The differences in the traditional rehabilitation model and the independent living philosophy are the basis for our "dream" of future services, and if I could take a minute, I'd like to describe them to you. (See Independent Living Paradigm).

Our ultimate dream for people with developmental disabilities is to get services in natural settings, that is, the same places that you and I go. If an adult needs

further education regarding budgeting, she could attend a class at a community college. If someone wants to exercise more, he joins the "Y" or perhaps a city recreational program. And if he needs a job, he/she has the same options as non disabled people. As laws such as the Americans with Disabilities Act become a reality, these will be options for many people.

For some of you this must seem very unrealistic. But the people we are talking about were all sent to institutions twenty five years ago. These very same people are now in supported apartments, supported employment, and many are living independently and working, just like us. Now, what changed for them? Did their IQ improve? No, what changed was our opinion about them. As our expectations increased, they learned, and their opportunities expanded. What a concept!

Our vision of the future is that all of us who are "stakeholders" in this room will provide employment services, assist with finding housing, assist with locating personal assistants, and provide support to ensure parents, teachers and others have the same expectations, hopes and dreams for their child with a disability that they have for their non disabled child.

What will this require? We believe it will come from ensuring that the most important "stakeholders", the people with disabilities and their families and friends, are the ones in control. This cannot happen if you, the legislature continue to give all the money to us, the providers. As you know, money equals control. When "consumers" have the money, they control what is produced.

In Kansas we currently have a monopoly established. Only community mental retardation centers (CMRC's) and their affiliates receive funding to provide services to people with developmental disabilities. Case managers, or the individuals who determine where you receive the services requested, work for the agencies who provide the requested service. If you are eligible for funding, and there are no "slots" available at the agency, you are put on a waiting list. If you are not eligible for funding for services, you may be referred to a CIL, or another provider.

If, instead, we had standards for who could be a provider, anyone in a given area who meets those standards could be "designated" a provider by the state. Eligible consumers/parents could receive vouchers from the state for the services they want, and have a list of where they could go to spend the vouchers. If I, as a consumer wanted supported employment from TARC in Topeka, and Independent living skills training from TILRC, I would have that choice. If I needed respite services, and I had vouchers to spend, providers would become available. Competition would improve services, making providers accountable to the consumer, just as other supports that you and I use are responsive to our needs or they go out of business. And it puts the "buying power" and the knowledge of services directly into the hands of the consumers and/or their families. Giving families and consumers knowledge about services and the ability to

purchase services which they feel have quality, will force us as providers to do a better job. That is true quality control. It is also true consumer control.

As long as we're dreaming, we would also like to see a system where people with developmental disabilities choosing to live in the community have access to quality health care. Currently, if you live in an institution, you have access to medical, dental, eye and other health care. If you are a prisoner, you have access to these services. But if you live in the community, you do not, unless you can afford private insurance, and if that private insurance company will cover you. KACIL would like to see a Medicaid buy in opportunity for people who have disabilities, allowing them to purchase additional services such as dental, eye care and assistive devices not covered, for a minimal expense. We would also like this system to reduce the disincentives for employment to people with developmental disabilities who, because they accept entry level jobs that provide little or no health insurance, will lose their medical cards because of their employment. Or even during the initial work period where they keep their Medicaid cards, the spend down is often so high that it is more efficient not get a job.

I would be happy to attempt to answer any questions you may have. I want to thank the Chair for including us in this discussion. We are working with people with developmental disabilities and their families. We receive federal money and can provide services today. We hope that we can continue to work with you to find solutions.

INDEPENDENT LIVING AND TRADITIONAL PARADIGMS

	MEDICAL MODEL & REHABILITATION PARADIGM	INDEPENDENT LIVING PARADIGM
Definition of problem	physical or mental impairment; lack of vocational skill (in the VR system)	dependence upon professionals, family members and others; hostile attitudes and environments
Focus of problem	in the individual (individual needs to be "fixed")	in the environment; in the medical and/or rehabilitation process itself
Solution to the problem	professional intervention; treatment	<ol style="list-style-type: none"> 1. barrier removal 2. advocacy 3. self-help 4. peer role models and counseling 5. consumer control over options and services
Social role	individual with a disability is a "patient" or "client"	individual with a disability is a "consumer" or "user" of services and products
Who controls	professional	"consumer" or "citizen"
Desired outcomes	maximum self-care (or "ADL"); gainful employment in the VR system	independence through control over ACCEPTABLE options for every day living in an integrated community

Originally developed by Gerben DeJong, adapted/expanded by Maggie Shreve, Organization Development Consultant

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Select Committee on Developmental Disabilities
Representative Jo Ann Pottorff, Chair
January 23, 1995
Shannon M. Jones, Executive Director, SILCK

My name is Shannon Jones, I represent the Statewide Independent Living Council of Kansas (SILCK). One of the primary responsibilities of the SILCK is to develop a Statewide network of independent living options for individuals with disabilities and increase the capacity of Centers for Independent Living (CIL's) to develop comprehensive approaches or systems for providing independent living services. Currently, there are 12 CIL's in the state that are available to serve the needs of individuals with developmental disabilities. However of those 12 Centers the majority do NOT receive referrals for independent living services from Community Mental Retardation Centers (CMRC's). Traditionally CMRC's have been seen as the only source available to provide services to people with developmental disabilities. Under this tradition, people from the DD population have never been given the CHOICE of available service options.

There are twelve CIL'S are located around the state. They are located in Wichita, Salina, Kansas City, Osage City, Topeka, Atchison, Hays, Dodge City, Parsons, Wamego and Lawrence. All CIL's provide four core services; independent livings skills training, peer counseling, information and referral, and individual and systems advocacy. Currently, Independent Connection in Salina serves over 100 people with developmental disabilities. Some of the services provided include apartment support for meeting the needs of individuals who wish to live independently and assistance with locating employment. The Topeka CIL and the Center in Hays, { LINK } also provide intensive support for people with developmental disabilities. They too, assist in providing training to individuals to live independently in their own apartment or their own homes. Currently the Topeka Center is working with local Banks to set up low interest loans so that individuals are able to purchase their own homes. These same services could be offered to a much larger degree, should CIL's have access to receiving the same reimbursement that CMRC's currently receive.

According to current State policy, CMRC's are the only recognized agency to receive funding for services. CIL's in total receive approximately 1.5 million dollars in State and Federal funds through the Rehabilitation Act, state general fund dollars and county mil

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Attachment 5*

levies. This same amount ,1.5 million dollars, is the approximate budget of one medium sized CMRC ! Just imagine how CIL"S could expand their services to individuals with developmental disabilities given that amount of money.

The SILCK wants to state that we are not asking to take away dollars from CMRC's. We are only asking that CIL"S be offered as a choice to individuals and their families. We want CIL's to be recognized as quality providers of independent living services as well . If CIL's were offered as an option people could receive services in a much more timely basis not have to be placed on waiting list.