Approved: March 8, 1995
Date

MINUTES OF THE HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES.

The meeting was called to order by Chairman Jo Ann Pottorff at 3:30 p.m. on January 25, 1995 in Room 522-S of the Capitol.

All members were present :

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

Conferees appearing before the committee: Josie Torrez, Legislative Liaison, Families Together, Inc.
Deb Voth, Early Childhood Developmental Servs.
Tom Laing, Exec. Dir. KARF
George Vega for SRS Secretary
Gary Blumenthal, Exec.Dir., Pres.Comm. on MR

Others attending: See attached list

Conferees continued presentation on developmental disabilities with an overview of history and current functions, along with future goals.

Josie Torrez, Legislative Liaison, Families Together, Inc. (Attachment 1)

Deb Voth, Chairman, Coordinating Council on Early Childhood Developmental Services (Attachment 2).

Tom Laing, Executive Director, The Kansas Association of Rehabilitation Facilities (Attachment 3). KARF's statement regarding quality assurance is on pages 3-12 and 3-13 of the attachment.

George Vega, Commissioner, SRS, Mental Health & Retardation Services did not bring written testimony as he has already talked to this committee. SRS sees this as a period of great change. SRS believes that current consumers and providers are the ones to "dream" for this committee. One constant wish which has been noted is also seen by SRS as the key to the future for the developmentally disabled; that is, employment opportunities in the communities. This is going to be the key for adult services. It provides social contact, friendships, money to support self, all the things that any adult obtains from employment.

Gary Blumenthal, Executive Director, President's Committee on Mental Retardation, Special Committee on Mental Retardation (Attachment 4). Mr. Blumenthal additionally commented that the Federal Government has special hiring provisions relating to persons with disabilities. Appointments under Schedule A exempt them from a variety of regulations which apply to other applicants. There are also Federal Union exemptions. It was suggested the State of Kansas might wish to consider similar hiring practices. From a federal perspective the most successful quality assurance takes place at the state level. Federal technical assistance is provided to states and Kansas recently received federal funds for protection and advocacy programs, etc. He strongly believes that in the not too far future states will be asked to justify every dollar expenditure tied in with federal funds and that you will be asked to come up with what is best for the individual and the overall system. He added that state legislatures need to send a strong message that the future is in community services as already you see people with the same or worse disabilities being served more effectively in the community than in hospitals. The "Contract with America" fits with what is trying to be done with the disabled population in the community. He believes the overwhelming majority of the developmentally disabled can be served in the community, but hospital closures must be planned and must be adequately supported in the community. This requires not only planning but training and funding.

The next meeting will be Wednesday, February 8, 1995 at 3:30 p.m. in Room 522-S.

Adjournment was at 5:00 p.m.

ADDENDUM: Jane Rhys' paper on definition of developmental disabilities and suggested bill language provided to committee members and staff (Attachment 5).

HOUSE SELECT COMMITTEE ON DEVELOPMENTAL DISABILITIES COMMITTEE GUEST LIST

DATE: January 25, 1995

NAME	REPRESENTING
Bill Britton	Starkey (Sg Co)
Ron Laing	
Martha Hodgesmith	KARF
Josie Torrez	Families Together, Inc.
Arika Aldrich	Resource Center for Independent Living
Jane Rhys	KS Council on Dev. Disabilities
Bob Geers	The Arc of Kansas
Sherry C Diel	Kansas Advocacy & Protective Services
Shannon Jones	SILCR
David W Powell	Rucker, Powell & Associates Ltd.
Lyn Rucker	RUCKER, Powell & Assoc.
[illegible]	JoCo. M.R. Center
Deb Voth	COORDINATING COUNCIL ON EARLY CHILDHOOD DEVELOPMENTAL SERVICES
Darwin Hirsch	SRS / MH&RS
George O. Vega	SRS/MHRS
Karla Taylor	Intern - 112th
James L. Germer	Ks. Advocacy & Protective Servs.

FAMILIES TOGETHER, INC.

PARENT CENTER:
* 501 Jackson, Suite 400
Topeka, KS 66603
(913) 233-4777 V/TDD
(913) 233-4787 FAX
1-800-264-6343 Toll free
in Kansas for parents

SATELLITE OFFICE
* 2312 S. Meridian, Su. 2
Wichita, KS 67213
(316) 945-7747
* 116 E. Chestnut, Suite 103
Garden City, KS 67846
(316) 276-6364

ASSISTING FAMILIES THAT INCLUDE A CHILD WITH A DISABILITY

To: House Select Committee on MR/DD

From: Josie Torrez, Families Together, Inc.

Date: January 25, 1995

My name is Josie Torrez and I am the mother of Chris, age 12 and Joey, age 9 who has autism. Some of the characteristics of autism are difficulty relating to people, insistence that the environment and routine remain unchanged, verbal and nonverbal communication skills are impaired, little imaginative play and impairment of social interaction development. Imagine life with no variety. Joey eats the same thing at breakfast each day at the same time, wears the same type of clothes but different colors, wears the same style of shoes, sits in the same place in our van (and heaven help us all if we need to take his Dad's car) and watches the same television shows before and after school. At school, his teacher does not move his desk around, although she does move other students around him. His teacher also prepares a schedule of daily activities (see attached sheet) so he knows what to expect at what time. This is very beneficial to Joey. Joey has a speech disorder which makes him difficult to understand. He also has low muscle tone which makes it difficult to walk long distances; he's much too heavy to carry now so we sit and rest a lot when on outings.

I work at Families Together, Inc. located here in Topeka. We are a Statewide organization that assists families in Kansas that include children or youth with disabilities. Of the staff of 17, 14 are parents of young people with disabilities. We have attached our brochure.

We have been asked to testify in regard to gaps in community services, dreaming from a family perspective and dreams of what needs to happen in the community. We have never been asked by the Legislature to dream before, so we're pretty excited that you have asked us to do this!

Some of the gaps that Families Together hear's from families in Kansas are that in some areas of the State, those responsible for advising parents of choices and options available for their child or youth with disabilities

House Select Committee on
Developmental Disabilities
1-25-95
Attachment 1

are not doing so. They are only offering services that they provide. Sometimes we find that people are being overserved when the services available are more than families want or need at this time. Sometimes we hear from families across the State who are told that the needs their child with a disability has or that the family has can not be met the way the family desires; although they can offer this and this, they can't offer that. When we meet with families and advise them of all the services available in their community, they are surprised that no one mentioned all of the possibilities before.

In the community, some gaps include day camps, swim lessons, ball teams, and day care. These community activities hesitate to enroll children with disabilities due to their lack of knowledge in providing support. There is so much educating that needs to be done in the community regarding the abilities of children and youth with disabilities. Often times we find that because a child may need a little more support, and because they have never taken a child with a disability in their program before, they are afraid of what they don't know.

Schools also have gaps wherein they are not doing what the law (94-142) requires. Individual education plans are not written properly to include the unique needs of children or youth receiving Special Education services. Transition plans for youth with disabilities over age 14 are often not being done correctly, and in some areas of the State, not at all.

There are also gaps in some churches in Kansas. These gaps include youth groups, bible study and Sunday School. Children with disabilities are left out, probably not intentionally, but left out nonetheless.

There are gaps in institutional settings where people with disabilities are being overserved with everything being provided. In the community setting, people with disabilities are being underserved. It's like pulling teeth to get the services we need.

Families that include a child or youth with a disability have dreams for their children just like other families. We may need a little more supports or services to fulfill those dreams, but we do dream.

We have contacted families across the State for some input on the dreams they have for their children. Please understand that each family that includes a child or youth with a disability are unique in the needs of their family. Some of those dreams are:

A family from Lawrence dreams that someone will provide effective future planning of coordinated services for their 20 year old son with Down Syndrome before he leaves the school system.

Another parent of a 4 1/2 year old from Wichita dreams that there will always be a person like the parent advocate at Families Together available to tell her about her child's rights and show her how to hold onto her dreams.

My family's dream for Joey is for a consistent person who will provide respite care so my husband and I can spend more time with each other or with our other son, Chris. Chris used to feel we loved Joey more than him due to the amount of time we must spend with Joey. Chris is older now and understands why we must spend additional time with Joey. Another dream we have for Joey is for him to reach the goals we have set for him; to be all that he can be (or like Joey says "All the be I can be") in school and church and to be a productive member of society with a job. If he wishes to live at home, that's fine with us. If he chooses to get an apartment, that's fine with us also.

We at Families Together find that parents and family members must think creatively when planning the future of their children. We must think well in advance and of every possibility. The job my husband and I envision for Joey is to work in a movie theatre. He will take the tickets from the customer, tear them in half and during the show, he will use a sweeper on the carpet. He will not have to make change, speak to people or make decisions. He also will be able to eat all the popcorn he wants and see movies free of charge on his days off, both of which he loves!

As Joey reaches high school age, we dream that he will have an attendant to take him to school and church events and begin to show him that he can be fine without Mom and Dad right there with him all the time.

Families want options and choices for their child or youth with a disability. We want these in community services, in how our kids live, learn, work and play in a barrier free, acceptable society. We are also finding that there is a new wave of parents who want their child/youth with a disability at home with them. Families have a positive vision for their child's future and when they are included in school, community, church and recreation, this helps to make our vision a reality.

Parent vouchers would give families a choice on the services for their children or youth with disabilities. We could then shop around for the best services available and choose the service that best meets our child's needs at that time in their life. This would provide for healthy competition on the part of service providers. We would then have the best possible services by the best providers. Services we want available through the parent voucher system could include attendant services, respite care, job training and health care services. If families could receive a menu of services available, they could pick and choose the services they need now.

We want the State of Kansas to support and promote family responsibility by supporting us to become self-sufficient when it comes to our children with disabilities.

Our dreams of what needs to happen will not cost any more money than is being spent presently. What we dream of will just split up the monopoly. All family support money does not have to go through to only one place; it could even go to families. The families know the needs of their child with a disability best. In my family's instance, the Topeka Association for Retarded Citizens (TARC) has a file on Joey and has for the past two years reimbursed us for respite care. They don't know the day to day needs of my family. How can they? They are doing the best they can.

Another dream that families have is self-directed care. We want to direct the care for our children, train the provider, schedule the providers and in some instances, teach our children how to self-direct the care they will receive in the future. Of course, there will always be families that can't self-direct their services and we will need to provide for them. But let's not "handicap" the families that can understand the system and creatively use the services available. Corporations are already being formed by families and advocates in our State that can give self-directed options to families through the MR/DD waiver. It's exciting to live in a State where this is possible. We dream of finding a way for all families to know of these innovative options. Let's use the ability of parents to make things happen. Let's not hold parents back by not giving them as much of the information as they can handle.

There were some comments last week in this committee wherein it was stated that parents may hire an attendant one day and fire that person the next day. We were insulted that this statement was made. If this does occur it is due to either abuse, neglect or stupidity on the part of the attendant. Parents shop for services and set up standards that the provider will live up to. Parents have a vested interest in their children and only want what is best for them.

When we speak of the needs of families we need to look at the individual, unique needs. Families generally will not ask for the sky, only what they need now. Whatever happens will cost less than institutional care.

What families need and want is a flexible, seamless, coordinated, collaborative and cooperative system wrapped around the unique individual needs of the child or youth with a disability and their family.

We need to address the needs of all people in Kansas with disabilities for them to achieve independence, and to enhance and improve their quality of life.

WEDNESDAY JANUARY 18, 1995

You did a really good job on behavior, especially since we did so many "active" out of seat things.

8:30-8:45	PENMANSHIP p. 97
8:45-9:15	MUSIC (Mrs. V. will pick you up. We will use the restroom afterwards.)
9:15-9:45	MRS. VAUSBINDER
9:45-10:15	RECREATIONAL READING (Read a book. Danielle, Dan, Kyle, Jesse, Isabell and Patricia go to Mrs. Rolsing)
10:15-10:30	READ ALOUD (Charlotte's Web Chapters 10 and 11)
10:30-11:30	MATH (Probability)
11:30-12:10	LUNCH/ RECESS (I have duty.)
12:10-12:30	LANGUAGE BOARDWORD
12:30-1:30	CHARLOTTE UNIT (Levers)
1:30-1:45	SHOW-AND-TELL (Megan, Isabell, Joe, and Danielle)
1:45-2:15	RESEARCH (Find levers in a magazine)
2:15-2:30	RECESS
2:30-3:25	WRITING (quotation marks) Joe to Mrs. Hall. Danielle and Sami to Mrs. Vausbinder.)
3:25-3:30	CLEAN-UP AND DISMISS

THINGS I NEED TO REMEMBER:

1. Read a book for 15 minutes.
2. Practice Spelling for 5 minutes.
3. Science page 137 "Lesson Review"
4. Math page 134

WHAT IS FAMILIES TOGETHER?

Families Together, Inc. is a statewide organization that assists families that include a child/youth with a disability. The program's mission is to offer families the security of belonging to a group of caring individuals with similar goals, challenges, and needs. Parents are informed as to the availability of resources and services throughout the state and receive assistance in making maximum use of such services. Families Together, Inc. provides a variety of activities for parents and family members of children/youth with disabilities to encourage change toward positive expectations.

Families Together, Inc. is dedicated to a society that includes and values all people. The Board of Directors and staff members are parents of children/youth with disabilities and advocates who believe that all students are entitled to support services, technology, and specifically designed instruction to assist them in realizing their capabilities and pursuing a full and satisfying life.

Families Together, Inc. is part of Project ber 1731212959A1 from the U.S. artment of Education, Special Education Programs, Department of Personnel Preparation.

HOW FAMILIES TOGETHER OFFERS ASSISTANCE

The Parent Training & Information Center in Topeka and the satellite offices in Wichita and Garden City provide literature, videos, and information on a variety of topics, such as:

- Acceptance/Awareness
- Assistive Technology
- Community Based Instruction
- Early Childhood
- Educational Rights
- IEP Development
- Inclusion
- Sibling Issues
- Specific Disabilities
- Support Groups
- Transition

Parents may call or come by any of the three offices for individual assistance with school and transition issues, questions about services, or for support from advocates or other parents of children/youth with disabilities.

Families Together also provides free workshops to parents, family members, teachers and other service providers. These workshops cover a variety of topics, including: early childhood services, preschool options, appropriate school age services, transition from school to work, and understanding and accessing state and federal financial aid programs. Workshops are scheduled during the school year and may be requested at any time.

Families Together sponsors several statewide conferences each year, where nationally known speakers gather with parents and service providers to share successes and achievements and to provide information on current issues of interest.

Families Together employs a legislative advocate who provides a voice for families with the state legislature. A legislative hotline may be called during the session (January through April) for information on relevant issues.

A newsletter is distributed quarterly to families and professionals who have requested to be on the Families Together mailing list.

A presentation by a board or staff member of the many Families Together services is available to organizations upon request.

8-1

___ YES, please add my name to the FAMILIES TOGETHER mailing list to receive the quarterly newsletter.

NAME ____________ ___ Parent ___ Service Provider

ADDRESS ____________________
(City) (County) (Zip)

TELEPHONE (   ) ________ If no phone, how can you be reached? ________

NAME OF CHILD WITH A DISABILITY ____________ DATE OF BIRTH __/__/__

CHILD'S DISABILITY ____________

OTHER CHILDREN IN FAMILY ____________ DATE OF BIRTH __/__/__

____________ DATE OF BIRTH __/__/__

____________ DATE OF BIRTH __/__/__

____________ DATE OF BIRTH __/__/__

Mail this form to: FAMILIES TOGETHER, INC., 501 JACKSON, SUITE 400; TOPEKA, KS 66603.

ADDITIONAL PROGRAMS

EDUCATION ADVOCATE PROGRAM: There are over 400 children with disabilities in Kansas whose parents are unknown or unavailable or whose parental rights have been terminated and who need someone to represent them in special education matters. The Kansas State Board of Education and Kansas State Department of Social and Rehabilitation Services have developed the Education Advocate Program to meet this need. Families Together coordinates the program through a contract with the Kansas State Board of Education.

CHILD ADVOCATE TRAINING PROGRAM: Families Together and the Kansas Department of Health and Environment have developed a Child Advocate Training Program to serve infants and toddlers (birth through age two) with disabilities whose parents are unknown or whose parental rights have been terminated. Families Together is responsible for providing the training for individuals interested in becoming child advocates for these children and also for the assignment of advocates to individual children.

TRANSITION SCHOOL TO WORK:
Families Together is actively involved with the Kansas grant from the Office of Special Education and Rehabilitation Services to provide systems change in school to work programs for students with disabilities. Opportunities are provided for students, family members, and Independent Living Center staff to work together to promote effective transition from school to adult living.

PARENT-TO-PARENT OF KANSAS:
This network coordinates the matching of "supporting" parents (who have experience parenting a child with a disability) with "newly referred" parents (who have just learned their child has a disability). Families Together provides assistance to existing Parent-to-Parent groups and in the development of new groups across the state.

FAMILIES TOGETHER, INC.

PARENT TRAINING & INFORMATION CENTER FOR KANSAS

501 JACKSON, SUITE 400
TOPEKA, KS 66603
(913) 233-4777 (Voice & TDD)
1-800-264-6343
(Toll free in Kansas for parents)

SATELLITE OFFICES:

2312 S. MERIDIAN, SUITE 102
WICHITA, KS 67213
(316) 945-7747

116 E. CHESTNUT, SUITE 103
GARDEN CITY, KS 67846
(316) 276-6364

ASSISTING FAMILIES THAT INCLUDE A CHILD WITH A DISABILITY

MAKE A Difference

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

Submitted by Coordinating Council on Early Childhood
Developmental Services (CCECDS)

Thank you for this opportunity to address service delivery options for individuals with developmental disabilities. My name is Deb Voth, and I am the Chair of the Coordinating Council on Early Childhood Developmental Services. In addition, I am the Associate Director of Rainbows United, Inc., an early intervention program in Wichita which provides a variety of services to individuals with developmental disabilities.

Federal legislation through The Individuals with Disabilities Education Act (IDEA) requires that a state interagency coordinating council be appointed by the Governor. The membership of the Kansas CCECDS includes a representative of the Governor, the Secretary of Social and Rehabilitation Services or a representative of the Secretary, the Secretary of the Department of Health and Environment or a representative of the Secretary, a member of the State Board of Education or the Commissioner of Education as its representative, the Insurance Commissioner or a repesentative of the Commissioner, two members of the State Legislature, parents and community providers.

The Council's main role is to advise and assist the lead agency for Part H, the Infants and Toddlers with Disabilities Program of IDEA. The lead agency in Kansas for Part H of IDEA is the Kansas Department of Health and Environment (KDHE).

Kansas legislation (KSA 74-7801 and KSA 74-7802) also addresses the formation of the CCECDS. In Kansas, the Council assists and advises agencies providing services to children, birth through five years, with developmental disabilities.

House Select Committee on 1-25-95
Developmental Disabilities
Attachment 2

Policy decisions are partially affected by current conditions, but also by the information available to policy makers during the planning process such as you are doing now. It is our hope that our Council will be of such assistance.

Years of research on children with various types of disabilities and receiving a range of individualized and specialized services has shown that early intervention services can (1) improve, and in some instances, prevent developmental delays from occurring; (2) result in fewer children being retained in later grades or needing special education services throughout their school life; (3) reduce educational costs to school programs and adult-related services; and (4) improve the quality of parent, child, and family relationships. (Smith, B. J., and Strain, P.S. (1988). Does early intervention help? <u>ERIC</u> <u>Digest</u> #455. Reston, VA: ERIC Clearinghouse on Handicapped and Gifted Children.)

In addition, we know that the most effective interventions are those that begin early in the child's life and address identified needs of both the child and the family.

Today, I would like to address our "dream" for the birth through five early intervention system. Our components include the following areas:

1) <u>Funding</u> - A main goal of the Part H system is "to capture any innovative funding strategies for serving infants, toddlers, and their families, by formulating an interagency funding plan. Dollars supporting services to children and families at the local level consist of federal, state, and local funding. Sources of funding include private insurance, medicaid, federal, state, and local educational dollars, state health dollars, county mill levy, private and public grants, donations, fundraising, and in-kind services. However, not all communities have equal access yet to all these state and local sources (i.e. state educational dollars and county mill levy).

2) <u>Local</u> <u>Decision-Making</u> - In addition to the required state coordinating council, local coordinating councils are required. There are currently 36 networks/councils throughout Kansas. These councils are responsible for bringing the community together so that (a) existing services can be identified; (b) resources such as funding, personnel, and programs can be utilized to their fullest; and

(c) families have a network of options available to them and their children. Additionally, these councils can help decide how federal and state funding can best be used and maximized in their communities. We strongly encourage the continuation of this community-sensitive approach.

3) <u>Family-Centered Services</u> - It is critical that families are the center of all decision-making processes. Families should have an array of options available to them and their children. We must continue to be sensitive to individual family needs.

4) <u>Seamless System</u> - The CCECDS is earnestly striving for a seamless system of early intervention services and funding. As families work through the complicated system of resources available to them and their children, it is our utmost responsibility to make (a) information readily available; (b) equal accessibility of services available to all eligible children and their families; and (c) smooth transitions possible for families and children as they move on from one or more delivery systems.

The Coordinating Council on Early Childhood Developmental Services is available to assist you in your quest for the very best options for individuals with developmental disabilities. We are proud of our accomplishments thus far. Even though our struggles are many, we are driven by the voices of our families and children in need of all our support and creativity.

Again, thank you for the opportunity to share some of the issues with you today.

MAKE A Difference

APPENDICES

Make A Difference Brochure

Infant and Toddler (Birth through 2 Years) Services Brochure

Preschool (3 through 5 Years) Services Brochure

Kansas Legislation (KSA 74-7801 and KSA 74-7802) for the Coordinating Council on Early Childhood Developmental Services

By-Laws for the Coordinating Council on Early Childhood Developmental Services (CCECDS)

Early Intervention Services in Kansas, 1993

Location of Part H Services in Kansas, 1993

Number and Type of Personnel Serving Part H in Kansas, 1993

December 1 Count of Children Served in Kansas

Funding Sources Sheet for Part H Services in Kansas as of 5/94

Written Comments from Deb Nelson, parent of a child with a disability and member of CCECDS

Growing Together Book - A Profile of Local Interagency Councils in Kansas

2-5

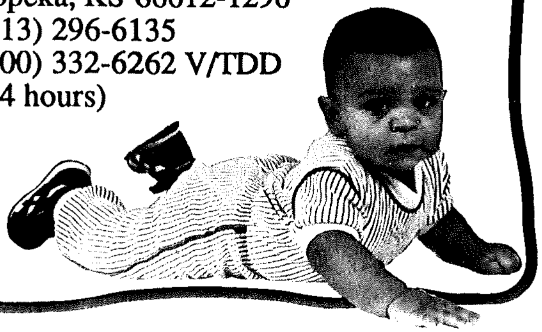
Where are the Services?

Services should be available in your community. The law requires that services be provided in places where your child would be if he or she did not have a developmental delay or a disability, including day care centers, in your home and in play groups.

How do you get more information?

Contact:

Kansas Department of
Health and Environment
Infant-Toddler Services
900 Southwest Jackson, Tenth Floor
Topeka, KS 66612-1290
(913) 296-6135
(800) 332-6262 V/TDD
(24 hours)



2-5

Kansas Department of
Health and Environment

Kansas Infant-Toddler Services
900 SW Jackson, 10th floor
Topeka, KS 66612-1290
For more information call:
1-800-332-6262

MAKE A DIFFERENCE FOR KANSAS KIDS

INFANT TODDLER SERVICES

IN KANSAS

hy are Infant-Toddler Services Important?

The first years of a child's life are the most important. Giving the right help to infants and toddlers can make a difference that lasts through their lifetimes.

Who is Eligible for Help?

Kansas families with infants or toddlers (from birth to three years of age) who have developmental delays or disabilities are entitled to early intervention services.

Is this Program for you and Your Child?

If you think you have a child with a disability, your family should take action. You should ask for a referral. Your family will work with a team to define your priorities, to inventory resources available to you and to discuss your child's strengths and needs. Your family, and an assessment and evaluation team, will work out an Individualized Family Service Plan (IFSP) that will define what you want for your child and how everyone will work together to achieve your family goals.

How do you get Help?

To get things started, call your local health department, school district, early intervention program, community medical facility or similar resource. You also may call the Make a Difference Information Network for help in locating local resources, 800-332-6262.

If your child needs services, your family will work with a team to discuss your priorities, the resources available to you, your child's strengths, and your concerns. Your family, and others working with your child, will write an Individualized Family Service Plan that will explain what you want for your child and how everyone will work together to reach your family goals.

What services are available?

Kansas has an early childhood intervention system. Local agencies can arrange for many services, including:

- Assistive technology
- Audiology
- Family service coordination
- Family information
- Health
- Medical
- Nursing
- Nutrition
- Occupational therapy
- Physical therapy
- Psychological services
- Social work
- Special instruction
- Speech-language pathology
- Transportation
- Vision

How Baby is Growing

Do you ever have questions about how your infant or toddler is growing and developing compared to other children? There is a checklist for growing children on the inside of this brochure to help you see how your child is growing.

It is never too soon to start following your child's development. The Infant-Toddler Early Intervention Program can help answer your questions.

On the Right Track

Since all infants and toddlers develop differently, parents may not know if their child is on the right track. Having your infant or toddler checked can help you find out if your child is developing at the right pace for his or her age.

If you have questions or concerns, now is the time to get them answered.

Checking can Make A Difference

It is important that you as parents are comfortable and satisfied with the growth and development of your child. If your child has special needs, early help can *make a difference*.

What Happens when Your Child is Checked?

"Child check" is a quick look at your child by professionals. They will check such things as: eyes, ears, general health, self-help skills, talking, communication, and other behaviors.

If your child needs further evaluation, or services from other professionals, a referral will be made so your child can get the necessary help.

Parents are involved in all aspects of their infant's or toddler's *child check*. A *child check* can help you make decisions that will *make a difference* about your child's future.

Scheduling a Child Check Appointment

Call one of the phone numbers listed below on this brochure or your local health department to make an appointment for your child. All parents of infants and toddlers, ages birth through two years, are encouraged to take advantage of the *child checks*.

If you have questions or want more information, please call

Make-A-Difference-Information Network
1 (800) 332-6262
TTY/TDD

The network can help you find the screening locations for your infant or toddler in your community.

1885

Infant-Toddler Program
Kansas Department of Health and Environment
Division of Health
Bureau of Family Health
Landon State Office Building
900 SW Jackson, 10th Floor
Topeka, Kansas 66612-1290
(913) 296-6135

W.M.M. 5/90

Checking to Make A Difference

Infant-Toddler Program
Kansas Dept. of Health and Environment
1 (800) 332-6262
TTY/TDD

A Checklist for Growing Children

are some of the signs of normal development for children between birth and three years of age. Remember, each child is different and may learn and grow at a different pace. These differences may or may not be cause for concern. As a parent you are the most important observer of your child's growth and development.

At 3 months, does your child:

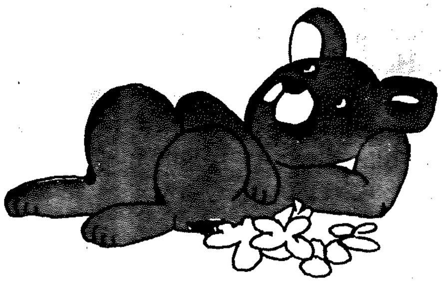
- ◇ turn head towards bright colors and lights
- ◇ follow moving object with eyes
- ◇ recognize bottle or breast
- ◇ respond to loud sounds
- ◇ grasp rattles or hair
- ◇ wiggle and kick with legs and arms
- ◇ lift head and chest while on stomach
- ◇ smile
- ◇ make cooing sounds

At 6 months, does your child:

- ◇ turn towards source of normal sound
- ◇ reach for toys and pick them up
- ◇ roll over (both ways)
- ◇ move toys from one hand to the other
- ◇ play with toes
- ◇ help hold bottle during feeding
- ◇ know familiar faces
- ◇ babble
- ◇ sit with minimum support

At 12 months, does your child:

- ◇ pull self to a standing position
- ◇ crawl on hands and knees
- ◇ drink from cup
- ◇ enjoy peek-a-boo and patty cake
- ◇ wave bye-bye
- ◇ put toys into containers
- ◇ say 1-2 words
- ◇ walk around furniture



At 18 months, does your child:

- ◇ like to pull, push, and dump things
- ◇ follow simple directions
- ◇ pull off shoes, socks, and mittens
- ◇ like to look at pictures
- ◇ feed self some
- ◇ use 8-10 words that are understood
- ◇ walk without help
- ◇ step off low objects and keep balance
- ◇ stack 2-3 blocks
- ◇ turn 2 or 3 pages at a time

At 2 years, does your child:

- ◇ use 2-3 word sentences
- ◇ say names of toys
- ◇ recognize familiar pictures
- ◇ feed self with spoon
- ◇ play alone and independently
- ◇ turn one page at a time
- ◇ like to imitate parents
- ◇ identify hair, eyes, ears, and nose by pointing
- ◇ build a tower of 6 blocks
- ◇ show affection
- ◇ run well

At 3 years, does your child:

- ◇ walk up steps alternating feet
- ◇ ride a tricycle
- ◇ dress with supervision
- ◇ open door
- ◇ play with other children
- ◇ repeat simple rhymes
- ◇ use 3-5 word sentences
- ◇ name at least one color correctly
- ◇ use toilet
- ◇ take turns
- ◇ hop on one foot

This brochure was developed as general guidance to support your enjoyment and understanding of your child's development. You may see small differences between your child and other children. Some differences may be explained by lack of experience with such things as swinging or riding a trike. However, if you notice what seems to be large differences in your child as compared to other children the same age, you may want to talk with someone about your concern. That may be your physician, someone at the health department, or at your neighborhood school.

Other things that are important for your child are:

- Up-to-date immunizations
- Regular dental checks and physicals
- Regular hearing and vision checks
- A balanced diet
- Plenty of rest
- Setting aside time to spend with your child, doing such things as reading or talking, and
- Noticing when your child is being good and praising that behavior.

You should enjoy your children!

These developmental growth milestones do not constitute a formal assessment tool. Rather, this information has been compiled using a variety of resources as general guidelines for families and careproviders.

Thanks to Juliann Cripe, Ph.D., and David Lindeman, Ph.D., of the Kansas University Affiliated Program for development of this brochure.

Scheduling an Appointment for Your Child

Call one of the phone numbers listed below on this brochure, your local health department, or local public school system, to make an appointment for your child. All parents of children, ages birth through 5 years, are encouraged to take advantage of the screening services in your community.

If you have questions or want more information, please call:

- Your local school system
- County Health Department
- Make-A-Difference-Information Network (800) 332-6262

This network can help you find a screening resource for your child in your community.

Contact

Preschool Grants Program
Special Education Outcomes Team
Kansas State Board of Education
120 S.E. 10th Avenue
Topeka, KS 66612-1182
(913) 296-7454

Infant-Toddler Program
Kansas Department of Health and Environment
Division of Health
Bureau of Family Health
Landon State Office Building
900 S.W. Jackson, 10th Floor
Topeka, KS 66612-1290
(913) 296-6135

Developmental Growth For Children

3 to 5 Years of Age

General Guidelines

Listed below are some skills that are signs of typical development for children between 3 and 5 years of age. Remember, each child is different and may learn and grow at a different pace. These differences may or may not be cause for concern. As a parent you are the most important observer of your child's growth and development.

At 3 years of age does your child:

THINKING AND MOVING

- Feed self with some spilling
- Wash and dry hands

- Take off simple clothes
- Mark purposefully with crayon
- Throw a ball over head
- Pedal a trike
- Look at books and turn pages
- Avoid some dangers such as hot

- Follow one-step directions

- Identify big and small

TALKING AND PLAYING

- Imitate familiar household tasks

- Play next to other children

- Claim and defend possessions
- Make most sounds understandable

- Use 3 to 5 word sentences

- Answer simple "wh" questions
- Join in laughter
- Know first and last names

At 4 years of age does your child:

THINKING AND MOVING

- Serve self food
- Brush teeth with help

- Put on simple clothes
- Copy lines, circles, and draw face
- Catch a bounced ball
- Swing unaided
- Point and name objects in books
- Move around immediate neighborhood
- Follow two- and three-step familiar directions
- Sort by shape and color

TALKING AND PLAYING

- Enjoy playing dress-up

- Share toys in play with others

- Follow simple rules
- May still make such common sound errors as "r", "s", "l", and blends "sl", and "cr"
- Combine two or more sentences

- Ask "wh" questions
- Tell simple stories
- Know age and gender

At 5 years of age does your child:

THINKING AND MOVING

- Use a fork and knife well
- Wash and dry face and brush teeth unaided
- Dress and undress unaided
- Draw simple figures
- Catch a tossed ball
- Jump over low objects
- Know simple songs or stories
- Cross the street safely

- Follow three-step unfamiliar instructions
- Name colors and numbers

TALKING AND PLAYING

- Engage in complex pretend play
- Initiate play and play with others
- Resolve conflicts with peers
- Can be understood by strangers

- Use past and future tense in complex sentences
- Answer "wh" questions
- Enjoy riddles and jokes
- Know phone number and address

•MAKE A• Difference INFORMATION •NETWORK•

The Make A Difference Information Network For Children And Adults With Disabilities is for anyone seeking information about the services and resources that are available in Kansas. It is a network of many cooperating programs. One phone call will reach all of these programs.

Information is available about:

- advocacy and legal organizations
- respite care during vacations, weekends or family emergencies
- screening, diagnosis, evaluation
- early intervention for infants and preschool children
- education, public health and social service agencies
- counseling
- parent support groups
- resource material for families
- benefits coordination
- local planning council
- technical assistance

Why Call The Make A Difference Information Network?

Information about services has been collected into one computerized system so that individuals and their families will not have to search for the services that they may need. The Make A Difference Information Network can help you find the right agency in your community to contact.

How Does The Network Help?

One toll free call will activate a computer search through the agencies and programs in your community and in the state which may be able to help you.

Then you will know:

- What is available
- Whom to call
- Where to go for help

What Will Happen Then?

You can decide what services to contact. No one will call or write to you unless you ask them to do so.

So Make That Call

Call if you need help finding information about services and resources for persons with disabilities.

Make A Difference Information Network

1-800-332-6262

The Make A Difference Information Network is made possible by the following sponsors

Advisory Commission on Children with Special Health Care Needs

Kansas State Board of Education
Special Education Outcomes Team

Kansas Department of Health and Environment

(WIC) Special Supplement Food Program for Women, Infants, and Children

Infant Toddler Program (P.L. 99-457, Part H)

Baby Your Baby Program

Please Be Seated Program

Immunization Program

Kansas Department of
Social and Rehabilitation Services
Office of Child and Adolescent
Mental Health Services Program

Other participants include:

Corporation for Change

Families Together, Inc., Parent Center

Keys for Networking

•MAKE A•
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INFORMATION
•NETWORK•

TDD/TT

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An Information Service for Children and Adults with Disabilities, their families, and their service providers.

•MAKE A•
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INFORMATION
•NETWORK•

1-800-332-6262

0-2yrs.

DECEMBER 1 CHILD COUNTS

Year	Total No. Served	Percent Increase
1990	491	
1991	650	32%
1992	853	31%
1993	1040	22%
1994	1193*	15%

* This total represents data from 34 of 36 networks. For the 2 missing networks, figures from 1993 tables were used.

Attached are copies of the tables of the PRELIMINARY child count. This count is not final, and will not be the one that goes to Washington, it is just to give you an idea of where we stand. I still need to do quite a bit of verification on kids that showed up two places. The counts may or may not go down, however--the program that produces these tables will only count a child once in each funding category, duplications across funding categories are the ones I have to check individually.

The Part B table shows all students being served in the public schools, including approximately 1,000 that previously would have been counted under Chapter 1 transfer. The Chapter 1 Total Table is the sum of three different counts, those being served by SRS, those being served by the prisons, and those being served in contracted agencies.

When our child count goes to Washington, it will be the sum of all of these, since they no longer are funding Chapter 1 Handicapped separately.

Comparison of years looks like this:

	December 1, 1993	December 1, 1994 **UNVERIFIED COUNT**
Part B Count (public schools)	47,489	50,790
(3-5 in Part B above)	(5,376)	(5,784)
Transfer Count (public schools)	1,128	In Part B above
SRS	612	573
Prison	18	27
KSBE Operated & Contracted	312	333
Total Federal Disabled	49,559	51,723
Gifted Only	13,662	13,975
Gifted Count that are also in Disabled	391	463
All Gifted	14,053	14438
Part H (0-2 Year Olds)	887	1,131

If you give this information to anyone, be sure to let them know it is not final. I should have final figures by February 1.

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(c) administer the Kansas crime victims assistance fund; and

(d) report to the legislature on or before February 1, 1996, regarding the use of moneys received from docket fees and credited to the crime victims assistance fund and the protection from abuse fund and recommendations for further assistance for programs receiving grants from such funds.

History: L. 1989, ch. 239, § 32; L. 1994, ch. 335, § 11; July 1.

Article 78.—COORDINATING COUNCIL ON EARLY CHILDHOOD DEVELOPMENTAL SERVICES

74-7801. Coordinating council on early childhood developmental services; composition; appointment; terms; vacancies; meetings. (a) The coordinating council on early childhood developmental services shall consist of not less than 16 nor more than 25 members as follows:

(1) A representative of the governor;

(2) the secretary of social and rehabilitation services or a representative of the secretary selected by the secretary;

(3) the secretary of health and environment or a representative of the secretary selected by the secretary;

(4) a member of the state board of education selected by the chairperson of the state board of education or, at the discretion of the chairperson of the state board, the commissioner of education;

(5) a representative of the board of regents selected by the chairperson of the board of regents;

(6) the commissioner of insurance or a representative of the commissioner selected by the commissioner;

(7) two members of the state legislature selected by the legislative coordinating council so that one is a member of the senate and one is a member of the house of representatives and such members are not members of the same political party; and

(8) not less than eight members nor more than 17 members appointed by the governor which members shall be selected to ensure that the requirements of 20 U.S.C. 1482 and amendments thereto are met.

(b) The members appointed by the governor under subsection (a)(8) shall serve for a term of four years. Members are eligible for reappointment.

(c) Any vacancy occurring in the appointive membership of the council shall be filled in the same manner and from the same class as the original appointment.

(d) A chairperson shall be designated annually by the governor. A vice-chairperson shall be designated by the chairperson to serve in the absence of the chairperson.

(e) Final decisions of the council shall be by majority vote of the members.

(f) The council shall meet at least quarterly.

History: L. 1986, ch. 281, § 1; L. 1989, ch. 240, § 1; L. 1994, ch. 279, § 29; July 1.

74-7802. Same; duties. The coordinating council on early childhood developmental services established by this act shall:

(a) Solicit information and opinions from concerned agencies, groups and individuals on proposed policies and recommendations for the delivery of health, education and social services for young children from birth through age five with or at risk for disabling conditions and for their families;

(b) establish appropriate committees to perform tasks, gather information and explore issues as directed by the council;

(c) determine the work activities of a staff person to the coordinating council on early childhood developmental services;

(d) disseminate information about the activities of the council and its actions to local, private and public service providers, parents, advocacy organizations, state agency personnel and other interested parties;

(e) develop and implement a state plan for young children from birth through age five with or at risk for disabling conditions and for their families;

(f) recommend policies, procedures and legislation for effectively providing health, education and social services;

(g) develop interagency agreements to promote a comprehensive service delivery system for young children with, or at risk for, disabling conditions and for their families;

(h) advise and assist the lead agency, as defined in K.S.A. 1994 Supp. 75-5648 and amendments thereto, in implementing the federal individuals with disabilities education act, Part H at both state and local levels; and

(i) submit annual reports to the governor.

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History: L. 1986, ch. 281, § 2; L. 1992, ch. 126, § 3; L. 1994, ch. 279, § 30; July 1.

74-7803. Expenses of appointed members; staff person, appointment, compensation, assignment. (a) The members of the coordinating council who are appointed by the governor under subsection (a)(8) of K.S.A. 74-7801 and amendments thereto shall be reimbursed for actual and necessary expenses incurred in the performance of their official duties in amounts provided for in subsection (e) of K.S.A. 75-3223, and amendments thereto. Amounts provided to be paid under this subsection shall be paid, subject to appropriations acts, from federal funds made available to the state for early childhood services for persons with disabilities.

(b) The coordinating council may appoint one staff person who shall be in the unclassified service under the Kansas civil service act and who shall receive compensation fixed by the coordinating council and approved by the governor. Such compensation shall be paid, subject to appropriations acts, from federal funds made available to the state for early childhood services for persons with disabilities. The staff person shall be assigned to the chairperson.

History: L. 1986, ch. 281, § 3; L. 1989, ch. 240, § 2; L. 1994, ch. 279, § 31; July 1.

Article 80.—KANSAS, INC.

Cross References to Related Sections:

Kansas economic opportunity initiatives fund, see 74-50,151.

74-8001. Creation; composition; ex officio members, designation; appointive members, qualifications, terms, vacancies. (a) There is hereby created a body politic and corporate to be known as Kansas, Inc. Kansas, Inc. is hereby constituted a public instrumentality and the exercise of the authority and powers conferred by this act shall be deemed and held to be the performance of an essential governmental function. Kansas, Inc. shall consist of 15 predominately private sector members as follows:

(1) The governor of Kansas;

(2) the secretary of the Kansas department of commerce;

(3) seven members who are appointed by the governor, subject to confirmation by the senate as provided in K.S.A. 75-4315b, and amendments thereto, as follows:

(A) One member from each of the primary economic sectors in the state—agriculture, oil and gas, and aviation—who are recognized fo outstanding knowledge and leadership in thei fields;

(B) one member from one other primary, jo creating, value added business sector who is recognized for outstanding knowledge and leadership in the member's field;

(C) two members from the private financia sector, one of whom shall have experience in the area of high-risk venture investments, and one o whom shall have commercial banking experience in an industry of special importance to the Kansas economy, and both of whom are recognized for outstanding knowledge and leadership in their fields;

(D) one member representing labor who is recognized for outstanding knowledge and leadership in the member's field;

(4) one member who serves as the commanding general of the Kansas cavalry;

(5) one member who is appointed by the state board of regents from a Kansas university and who is recognized for outstanding knowledge and leadership in the field of economic development;

(6) the speaker of the house, the house minority leader, the president of the senate, and the senate minority leader or legislators who are appointed to represent them and who will provide continuity by virtue of their membership on the standing committee on commerce of the senate, the standing committee on economic development of the house of representatives or the joint committee on economic development.

(b) (1) State officers who are designated as members of Kansas, Inc. under subsection (a)(1), (a)(2), (a)(4) and (a)(6) shall serve by virtue of office or position.

(2) Members appointed under subsection (a)(6) shall be appointed for a term ending on the first day of the regular legislative session in odd-numbered years.

(3) The member appointed under subsection (a)(5) shall serve for a term of four years.

(4) Members appointed under subsection (a)(3) shall serve for a term of four years, except that, of the members first appointed, two shall serve for a term of two years, three shall serve for a term of three years, and two shall serve for a term of four years.

(5) In case of a vacancy in the appointive membership of Kansas, Inc., a successor shall be appointed in like manner and subject to the same

BYLAWS OF THE KANSAS INTERAGENCY COORDINATING COUNCIL

ARTICLE I. MISSION OF THE COUNCIL

The mission of the Kansas Coordinating Council on Early Childhood Developmental Services is to ensure that a comprehensive service delivery system of integrated services is available in Kansas to all children with or at risk for developmental delays from birth through age 5 and their families.

ARTICLE II. VALUES OF THE COUNCIL

Early intervention provides the necessary services to enable young children who experience or are at risk for developmental delays to progress toward the maximum of their abilities. When these services are provided in a timely and appropriate manner, and in the context of the family, the need for further intervention can often be eliminated or reduced.

The family should be the primary focus in assessment and intervention activities. Collaboration with the family is essential to meet the developmental needs of young children.

Recognizing the variable nature of young children's performance and the potential for rapid change in their developmental status, assessment and diagnosis should be undertaken with caution. Assessment should focus on children's developmental needs and be linked directly to intervention. Consequently, administrative structures and funding mechanisms for services to young children should not require assigning specific diagnostic labels.

No single agency is capable of meeting all of the needs of young children with or at risk for developmental delays. The utilization of interagency collaboration is essential and will produce the most comprehensive and uninterrupted service. These services should be multi-disciplinary, and to the maximum extent appropriate, delivered in settings which are typical for young children and which include a predominance of normally developing children.

ARTICLE III. FUNCTIONS OF THE COUNCIL

As provided in K.S.A. 74-7802, as amended, the Council will:

l. Solicit information and opinions from concerned agencies, groups and individuals on proposed policies and recommendations for the delivery of health, education and social services for young children from birth through age five with or at risk for developmental delays for their families.

2. Establish appropriate committees to perform tasks, gather information, and explore issues as directed by the Council.

3. Determine the work activities of a staff person to the Coordinating Council on Early Childhood Developmental Services.

4. Disseminate information about the activities of the Council and its actions to local, private and public service providers, parents, advocacy organizations, state agency personnel and other interested parties.

5. Develop and implement a state plan for young children from birth through age five with or at risk for developmental delays and for their families.

6. Recommend policies, procedures, and legislation for effectively providing health, education and social services.

7. Develop interagency agreements to promote a comprehensive service delivery system for young children with developmental delays and for their families.

8. Advise and assist the lead agency, in implementing the Individuals with Disabilities Education Act (IDEA), Part H at both state and local levels: and

9. Submit an annual report to the Governor.

ARTICLE IV. MEMBERSHIP

The membership of the Kansas Coordinating Council shall consist of representatives of the public and private sector who by virtue of their position, interest and training can contribute to the quality of services provided to children with developmental delays and their families. The council shall be composed of at least 15 members, but not more than 25 members, and will include:

l. a representative of the Governor;

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2. the secretary of social and rehabilitation services or a representative selected by the secretary;

3. the secretary of health and environment or a representative selected by the secretary;

4. a member of the state board of education selected by the chairperson of the state board of education or, at the discretion of the chairperson, the commissioner of education;

5. a representative of the board of regents selected by the chairperson of the board of regents;

6. two members of the state legislature selected by the legislative coordinating council so that one is a member of the Senate and one is a member of the house of representatives and such members are not members of the same political party

7. a member of the state insurance commission; and

** 8. ten members appointed by the governor, four of whom are parents of children with developmental delays seven years of age, four of whom are providers of early childhood services for children with developmental delays; and; two of whom are representative of the public at large. One of these additional appointees must be involved in personnel preparation.

** Note: Federal regulations for Part H indicate that parent membership must be composed of "parents, including minority parents, of infants or toddlers with disabilities or children with disabilities aged <u>12 or younger, with knowledge of, or experience with, programs for infants and toddlers with disabilities. At least one member must be a parent of an infant or toddler with a disability or a child with a disability aged six or younger.</u>

A. TERM OF OFFICE

Members appointed by the governor shall serve a term of four years, Members are eligible for reappointment.

B. **TERMINATION**

Failure to attend three (3) consecutive meetings in a year shall result in a review by the Council for possible recommendation to the governor of termination.

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C. VACANCIES

Any vacancy occurring in the appointive membership of the council shall be filled in the same manner and from the same class as the original appointment. The Council, through the Council Chairperson, shall inform the Governor or the Legislative Coordinating Council within thirty (30) calendar days of any vacancy. Recommendations for filling said vacancy from the Coordinating Council shall be forwarded to the Governor.

D. RESIGNATION

A Council member's resignation must be in writing and shall be submitted to the appointing authority and to the Council Chairperson.

ARTICLE V. EXECUTIVE COMMITTEE AND OTHER COMMITTEES

A. EXECUTIVE COMMITTEE

The Executive Committee shall consist of the Council Chairperson, the Vice Chairperson, and four members to be elected by the Council from the membership. The Executive Committee shall:

a. Be responsible for handling emergency matters requiring immediate Council attention between officially scheduled meetings.

b. Execute any other functions, duties and responsibilities delegated to it by the Council Chairperson.

B. STANDING COMMITTEES

There Shall be six standing committees of the Coordinating Council:

a. Political Awareness Committee

b. Public Awareness Committee

c. Funding Committee

d. Personnel Committee

e. Data Management Committee

f. Membership Committee

C. ADVISORY COMMITTEE

The Advisory Committee shall consist of parent and provider representation, as approved by the Council, and shall meet quarterly. The Advisory Committee shall:

a. Advise and assist the Coordinating Council from a consumer's point of view.

b. Execute any other functions, duties and responsibilities delegated to it by the Council.

D. TASK FORCES\WORK GROUPS

a. When necessary, the Council shall be aided in its work by Task Forces or Work Groups. Membership shall consist of persons appointed by the Council.

b. Task Forces/Work Groups are intended to be task specific. They are expected to review issues and topics as assigned by the Council and to make recommendations to the Committees and then to the Council.

ARTICLE VI. MEETINGS OF THE COUNCIL

A. **SCHEDULE:** The Council shall meet at least quarterly. Additional meetings may be scheduled at other times and places as determined by the Council Chairperson.

B. **QUORUM:** A quorum consists of a simple majority of the full council membership. The Council may take official action only when a quorum is present. Final decisions of the council shall be by majority vote of the members.

C. **CHAIRPERSON:** The Chairperson shall be nominated by the Council as a whole at the July quarterly meeting. The nomination shall be forwarded to the Governor who will confirm the nomination or appoint a chairperson of the Governor's own choosing. Any member of the Council who is a representataive of the lead agency may not serve as the chairperson of the Council. The Chairperson is a full participating member of the Council and shall:

a. Be responsible for developing meeting agendas, scheduling meetings and ensuring completion of all tasks associated with Council meetings;

b. Preside over all meetings of the Council and the Executive Committee;

c. Vote on any matter submitted to a vote of the Council membership; and

d. Perform all duties incident to the position of Chairperson and all other duties as may be prescribed by the Council.

D. VICE-CHAIRPERSON: The Chairperson, upon considering the recommendation of the Council, shall appoint a Vice Chairperson. The Vice Chairperson is a <u>full participating member</u> of the Council who shall:

a. In the Chairperson's absence, perform the duties of the Chairperson;

b. When the Vice-Chairperson is active as Chairperson, he/she shall have all the powers of and be subject to all the restrictions upon the Chairperson; and,

c. The Vice-Chairperson shall be a member of the Executive Committee and shall perform any other duties that may be assigned by the Council Chairperson or by the Council.

E. VOTING

a. Each Council member is entitled to one vote on each matter submitted to a vote. Voting by proxy is permitted, but only through another Council member or designated representative as allowed by statute;

b. A vote of the majority of a quorum is necessary to approve any action taken by the Council. In the event of a tie vote the motion fails.

F. CONFLICT OF INTEREST

No member shall cast a vote on any matter which would provide financial benefit to that member or otherwise give the appearance of a conflict of interest under State Law.

G. EXPENSES

The members of the Coordinating Council who are appointed by the Governor shall be reimbursed for actual and necessary expenses, incurred in their performance of their official duties in accordance with section (e) of K.S.A. 75-3223 and amendments thereto.

H. PUBLIC PARTICIPATION

Public participation is deemed vital to the effective functioning of the Council. Within appropriate constraints determined by the Chairperson, thirty minutes of each meeting of the Coordinating Council shall be set aside for public participation. Persons wishing to address the Council will be asked to notify the Coordinator by the morning of the meeting.

Council meetings must be publicly announced sufficiently in advance of the dates they are to be held to ensure that all interested parties have an opportunity to attend. To the extent appropriate, these meetings will be open and accessible to the general public.

Special accommodations will be provided at Council meetings for Council members and public participants, upon notification made to the Coordinator one week in advance of the meeting.

I. PLACING ITEMS ON THE AGENDA

Any Council member wishing to place an item on the agenda, should notify the Coordinator at least two weeks in advance. This will allow time for any background materials to be assembled. The agenda will be mailed at least one week prior to the meeting. The Chairperson has the prerogative to add to the agenda at any time.

J. MINUTES

Minutes of the Council meetings shall be written and available for public inspection within fifteen working days, or prior to the next convened meeting, whichever occurs first.

Copies will be printed and mailed to Council members, local ICC contacts, and those who have requested minutes within fifteen working days.

ARTICLE VII. AMENDMENTS

These bylaws may be altered, amended or repealed and new bylaws may be adopted by formal action of the Council at any regular or special meeting of the Council. Proposed changes shall be submitted in writing to the Council Chair or Coordinator and received by all members of the Council at least 15 days prior to the scheduled meeting at which action is to be taken.

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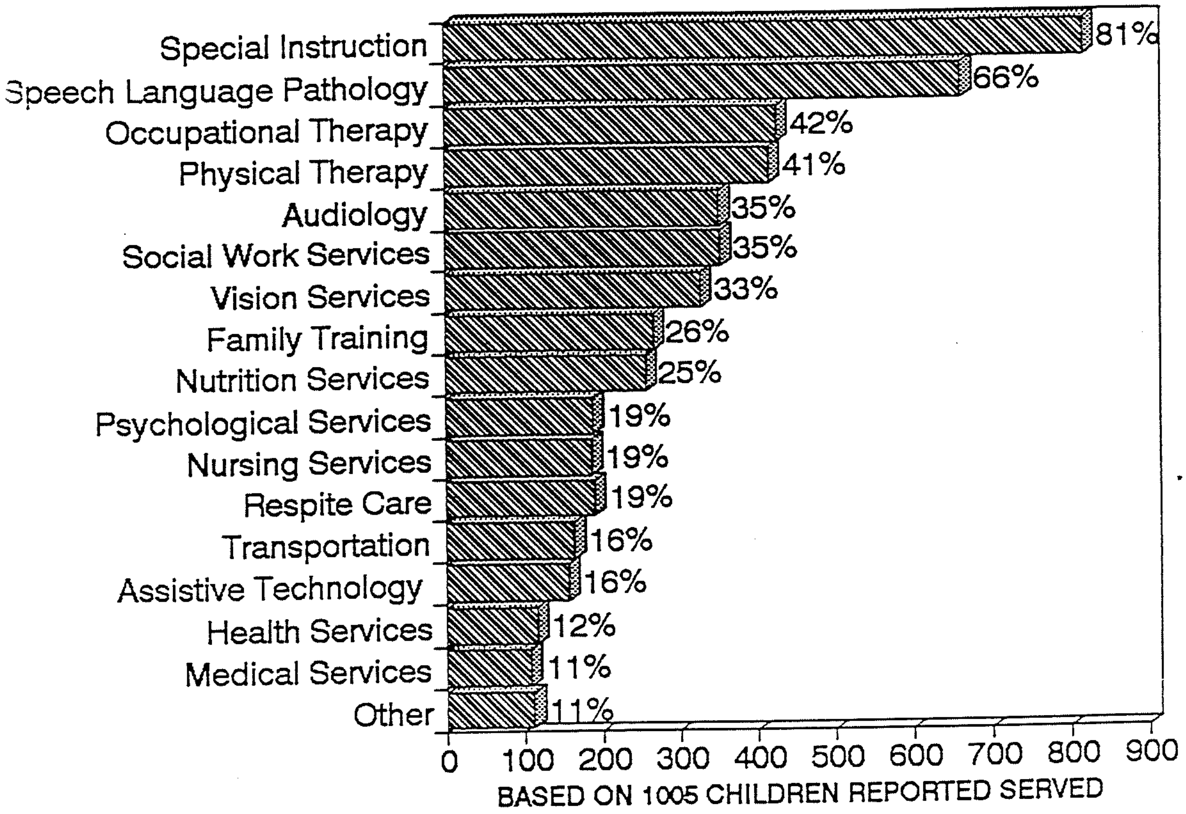
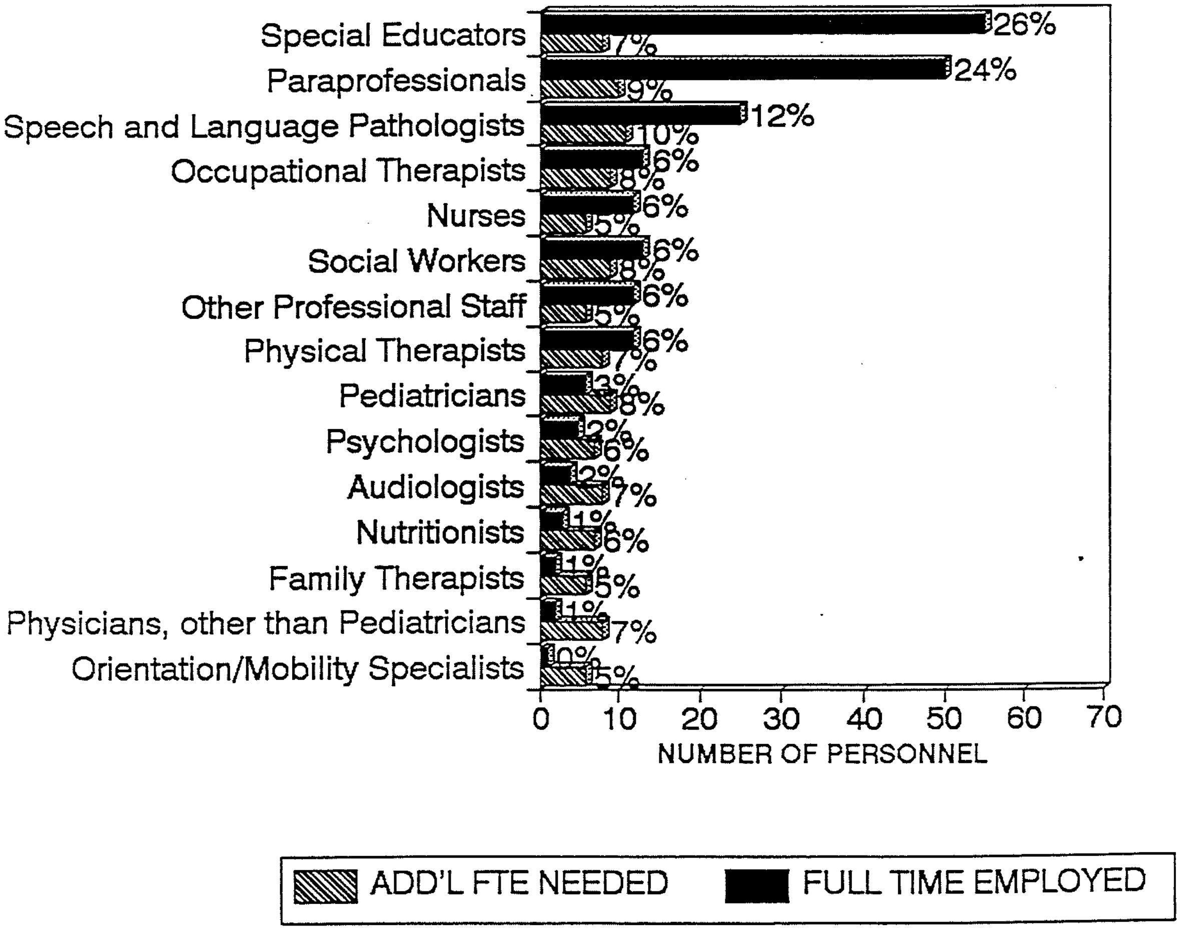
EARLY INTERVENTION SERVICES IN KANSAS, 1993



BASED ON 1005 CHILDREN REPORTED SERVED

SOURCE: DECEMBER 1993 FEDERAL DATA REPORT TABLE 2

NUMBER AND TYPE OF PERSONNEL SERVING PART H IN KANSAS, 1993



SOURCE: DECEMBER 1993 FEDERAL DATA REPORT TABLE 3

IDEA Part B 101-476 Students in Service on December 1, 1994

Age by Area of Exceptionality

PRELIMINARY CHILD COUNT

Checks for duplicates across districts are not complete. Adjustments to this report may be necessary. The final report will be sent after this process is completed.

Agency: **ALL**

USD: **ALL** **Summary all Coops**

City:

Special Ed Administered by:

	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22+	Total
Aut	3	5	5	15	19	26	21	20	14	15	15	10	5	6	4	3	3	3	0	0	192
BD	0	2	28	86	174	256	331	372	442	455	517	567	561	406	297	144	43	4	1	0	4686
DB	0	0	0	1	0	2	3	4	0	3	1	0	1	1	1	1	1	1	0	0	20
DD	0	1	4	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	5
EC	855	1448	968	138	7	0	0	1	0	0	0	0	0	0	0	0	0	0	0	2	3419
EM	12	8	42	178	290	339	358	375	395	407	363	397	347	326	259	203	82	16	7	0	4404
HI	10	12	18	26	32	38	28	33	37	35	54	33	36	25	31	9	7	0	0	0	464
IN	0	0	0	0	0	0	0	1	0	2	0	0	1	0	1	0	0	0	0	0	5
LD	0	1	27	170	700	1310	1932	2197	2285	2274	2086	1995	1857	1615	1365	786	160	10	1	1	20772
MA	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	1
OH	2	3	24	87	145	155	171	196	166	141	122	143	120	85	61	45	10	1	0	0	1677
OT	2	16	22	21	15	15	13	4	4	2	3	1	3	0	0	0	0	0	0	0	121
PI	5	16	22	39	29	36	41	35	40	30	18	12	23	25	26	5	4	1	4	0	411
PT	2	3	5	12	5	9	0	2	1	11	4	2	0	2	0	1	1	0	0	0	60
SL	237	532	1346	1884	1834	2228	1899	1188	693	375	170	103	51	34	18	15	1	0	0	5	12613
SM	6	9	23	28	24	46	44	41	27	32	42	32	28	21	20	15	19	13	7	0	477
TBI	7	8	9	11	13	13	14	17	16	17	20	16	16	14	14	7	5	3	1	0	221
TM	5	3	18	25	40	68	61	57	70	90	79	91	81	92	79	73	58	34	18	1	1043
VI	1	2	7	14	11	15	16	24	10	25	12	15	18	8	15	6	0	0	0	0	199
Tot	1147	2069	2568	2735	3338	4556	4932	4567	4200	3915	3506	3417	3148	2660	2191	1313	394	86	39	9	50790

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Chapter 1 State Sponsored Students in Service on December 1, 1994

Age by Area of Exceptionality

PRELIMINARY CHILD COUNT

Checks for duplicates across districts are not complete. Adjustments to this report may be necessary. The final report will be sent after this process is completed.

Agency: **ALL** **Summary all Buildings**

Special Ed Administered by: **7 0 0** – SRS

	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	Total
Aut	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	0	0	2
BD	0	0	0	0	0	1	3	2	9	8	14	17	25	46	51	63	85	56	26	5	3	0	414
DB	0	0	0	0	0	0	0	0	0	0	1	3	0	2	0	0	0	1	0	2	0	0	9
DD	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
EC	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
EM	0	0	0	0	0	0	0	0	0	0	1	0	0	1	2	3	0	6	1	0	2	1	17
HI	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1
IN	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
LD	0	0	0	0	0	0	0	0	0	0	0	2	1	0	1	7	5	9	1	0	0	0	26
MA	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
OH	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0	3
OT	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
PI	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
PT	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
SL	0	0	0	0	0	0	0	0	1	0	0	1	0	0	0	2	0	0	0	0	0	0	4
SM	0	0	0	0	1	0	0	0	3	0	1	5	6	4	10	3	6	8	13	3	11	7	81
TBI	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
TM	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	1	3	1	5	3	1	0	16
VI	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Tot	0	0	0	0	1	1	3	2	13	8	18	28	32	54	66	80	99	81	47	15	17	8	573

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Chapter 1 State Sponsored Students in Service on December 1, 1994

Age by Area of Exceptionality

PRELIMINARY CHILD COUNT

Checks for duplicates across districts are not complete. Adjustments to this report may be necessary. The final report will be sent after this process is completed.

Agency: **ALL** **Summary all Buildings**

Special Ed Administered by: **750** – PRISON

	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	Total
Aut	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
BD	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	6	3	6	2	18
DB	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
DD	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
EC	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
EM	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
HI	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
IN	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
LD	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	4	3	0	8
MA	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
OH	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
OT	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
PI	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
PT	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
SL	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1
SM	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
TBI	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
TM	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
VI	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Tot	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	6	8	9	2	27

Chapter 1 State Sponsored Students in Service on December 1, 1994

Age by Area of Exceptionality

PRELIMINARY CHILD COUNT

Checks for duplicates across districts are not complete. Adjustments to this report may be necessary. The final report will be sent after this process is completed.

Agency: **ALL** **Summary all Buildings**

Special Ed Administered by: 777 — KSBE CONTRACTED AGENCIES

	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	Total
Aut	0	0	0	0	0	0	0	0	3	0	0	0	0	1	0	0	0	0	0	0	0	0	4
BD	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	1	1	0	0	0	0	4
DB	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	2
DD	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
EC	0	0	0	31	14	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	45
EM	0	0	0	0	2	0	0	0	1	0	0	4	1	3	9	3	4	3	3	3	0	0	36
HI	0	0	0	2	4	6	4	3	9	5	11	9	15	16	15	22	10	20	13	5	1	0	170
IN	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
LD	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
MA	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
OH	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
OT	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
PI	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
PT	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
SL	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
SM	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	2	1	2	0	0	0	0	6
TBI	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	1	4	5	3	0	0	0	15
TM	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	5	3	1	1	5	2	3	21
VI	0	0	0	0	0	0	1	4	2	2	3	2	2	1	0	4	1	0	2	1	0	0	25
Tot	0	0	0	37	23	6	5	8	15	7	14	15	19	22	25	37	24	32	22	14	4	4	333

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Chapter 1 State Sponsored Students in Service on December 1, 1994

Age by Area of Exceptionality

PRELIMINARY CHILD COUNT

Checks for duplicates across districts are not complete. Adjustments to this report may be necessary. The final report will be sent after this process is completed.

Agency: **ALL** **Summary all Buildings** (TOTAL OF 700, 750, 777)

Special Ed Administered by: **ALL** **State Summary**

	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	Total
Aut	0	0	0	0	0	0	0	0	3	0	0	0	0	1	0	1	0	0	0	1	0	0	6
BD	0	0	0	0	0	1	3	2	9	8	14	17	25	47	52	63	86	58	32	8	9	2	436
DB	0	0	0	0	0	0	0	0	0	0	1	3	0	2	0	0	0	1	0	2	1	1	11
DD	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
EC	0	0	0	31	14	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	45
EM	0	0	0	0	2	0	0	0	1	0	1	4	1	4	11	6	4	9	4	3	2	1	53
HI	0	0	0	2	4	6	4	3	9	5	11	9	15	16	15	22	10	20	14	5	1	0	171
IN	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
LD	0	0	0	0	0	0	0	0	0	0	0	2	1	0	1	7	5	10	1	4	3	0	34
MA	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
OH	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	1	0	0	3
OT	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
PI	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
PT	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
SL	0	0	0	2	0	0	0	0	1	0	0	1	0	0	0	2	0	0	0	1	0	0	7
SM	0	0	0	0	2	0	0	0	3	0	1	5	6	4	10	5	7	10	13	3	11	7	87
TBI	0	0	0	0	0	0	0	1	0	0	0	0	1	0	0	1	4	5	3	0	0	0	15
TM	0	0	0	0	1	0	0	0	0	0	1	0	0	0	1	6	6	2	6	8	3	3	37
VI	0	0	0	0	0	0	1	4	2	2	3	2	2	1	0	4	1	0	2	1	0	0	25
Tot	0	0	0	37	24	7	8	10	28	15	32	43	51	76	91	117	123	115	75	37	30	14	933

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Students in Gifted Programs on December 1, 1994

Age by Area of Exceptionality

PRELIMINARY CHILD COUNT

Checks for duplicates across districts are not complete. Adjustments to this report may be necessary. The final report will be sent after this process is completed.

Agency: **ALL**
USD: **ALL** **Summary all Coops**

City:
Special Ed Administered by:

	6	7	8	9	10	11	12	13	14	15	16	17	18	19+	6-11	12-19+	Total
GI	36	154	447	778	1129	1517	1598	1750	1788	1593	1459	1346	376	4	4061	9914	13975
GI+	1	13	29	58	71	73	54	51	42	27	24	13	7	0	245	218	463
Tot	37	167	476	836	1200	1590	1652	1801	1830	1620	1483	1359	383	4	4306	10132	14438

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FUNDING SOURCES FOR COMMUNITY NETWORKS

	H&E. Part	H&E.SHS	H&E.Misc.	Chapter1	EDCatAide	EDTransp.	ED.Misc.	ED.LEA	CityCOloc	Medicaid	Misc. SRS	Insurance	UnitedWay	GrantsETC	MISC.	Total	dec1kids
Arrowhead	49830			23069	124898	26350									124116	3482	72
Atchison	8200																1
Butler CO	33160									6432	11400	2500			3750	57242	11
Elk/Chaut	8098			3000	16942	5250			9384		500					43174	7
Coffey CO	15877				7880	246			450	560				1500		26513	5
Douglas C	38685		20177	7038	19700		13097		35945	3249	15155	7513	170			160729	34
NW Ks EC	26971			7045	196212	1495	19000		20000							270723	14
E. Central	25724			1564	34475	2500										64263	14
Five CO	44011	200					200		1696	13734	400	52155				112396	14
Emporia	38450			4000	51023	2400		4813		1150						101836	17
Geary CO	68670	3660		794	0	0	420		16721	15232	81000			1000	6600	194097	32
Harv.y CO	22801		2434	1955	50235	1707			47751		325					127208	28
Hays	15475			6300	102243				157395	750		5000	17500			304663	23
Johnson C	102310			16100	44325	2100	95000		5100			5054		4000		273989	83
Kid Link	25545			7820	0		48000									81365	30
Leavenwor	34649						47500								61100	143249	26
Manhattan	32720			2000	91802	6000	0			200						132722	20
Marion	10716	100	500	1170	6698		100		1250	400	500	450		200		22084	9
McPherso	13242			9000	19700	2850	47500		76093	250				300		168935	24
NE KS ES	14606			1955	7486	1824			5450							31321	9
NorthCentr	9710								2400	3600				2140		17850	6
Osage CO	11486			4500	24625	3000			1250		500					45361	13
Ottawa	18269			1868	19700	93			10750	7580	5241			260		63761	7
PACT	12767			4692	19700		7600		8000				6384			59143	15
Pott/Waub	20179				58706	2000			3920	120	1400	7450		3500		97275	14
PrairieBan	11098														15000	26098	2
REACH	32720			10166	60676				83190					16807	104046	307605	31
Reno CO	32720			22668	106380	4000			16947				35000	90000		307715	39
Salina	58414								70825	25000	20000	71435	38170	500	24300	308644	63
Sedgwick	211674			24000		100000	285000		477090	40000	80676	30000	358565	44800	36600	1688405	142
SE Ks ESC	90149			17500	127656	26000			1650							262955	70
SW KS Ru	49947			33000	129258	13900			147500		400					374005	97
Sumner C	15592		15000	5474	69541	19020			97400							222027	12
Sunflower	27206		1000	15000					240265		80000				2000	365471	52
Shawnee	90149			24701					122879		21467	18000	33515	95380		406091	71
Wyandotte	111181				243295	35000	38000									427476	86
TOTAL	1433001	3960	39111	256379	1633156	255735	601417	4813	1661301	118257	318964	199557	489304	260387	377512	7652854	1193

5/94

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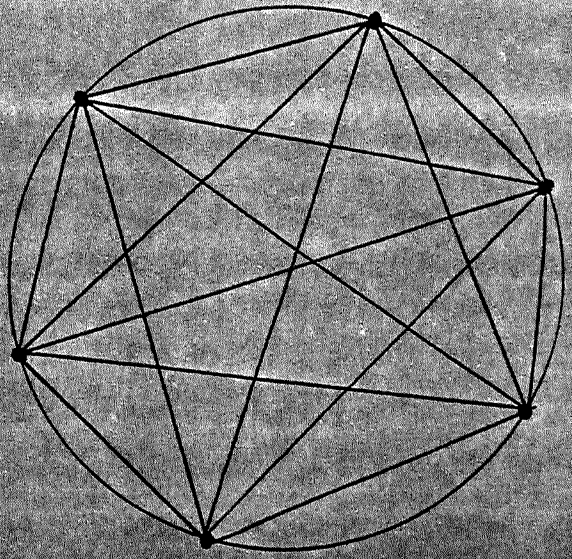
GROWING TOGETHER



A Profile of Local Interagency Councils in Kansas Planning for Children Birth through Age Two and Their Families

May 1994

Prepared for the Kansas Department of Health and Environment
by Bridging Early Services Transition Project
Associated Colleges of Central Kansas
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PREFACE

The authors of this Profile acknowledge pioneering work on local interagency efforts for very young children and their families. These efforts include a local interagency coordinating council taskforce coordinated by Judy Moler, Elaine Washburn, and Sharon Rosenkoetter which met in 1990-92 and a 1993 report written by Josie Torrez with the help of Pat Barber, Elaine Washburn, and the staff of Infant-Toddler Services at the Kansas Department of Health and Environment. The 1993 report described each of the local infant-toddler networks and provided an initial framework for the current Profile.

We also deeply appreciate the time commitment and graciousness in responding of local contact persons across Kansas. They agreed to be interviewed, edited transcripts, and provided additional information as requested, in the hope that their experiences with interagency efforts will be useful to families and service providers in other parts of the State.

This report has been prepared by staff of the Bridging Early Services Transition Project, an outreach project of the U.S. Department of Education housed at the Associated Colleges of Central Kansas (ACCK). Funds were provided by grant #HO24D30046 to ACCK and by the Kansas Department of Health and Environment.

Additional copies of <u>Growing Together</u> may be ordered by contacting the Make A Difference Information Network at (800) 332-6262; Diane Alexander, Infant-Toddler Services, KDHE, Landon State Office Building, 900 SW Jefferson, Topeka, KS 66612, (913) 296-6135; or Bridging Early Services Transition Project, ACCK, 105 E. Kansas, McPherson, KS 67460; (316) 241-7754.

EXECUTIVE SUMMARY

"It is the dream articulated that will shape our communities."
--Lisbeth Vincent

Services to infants and toddlers with special needs and their families in Kansas depend on community networks guided by local interagency coordinating councils. These LICCs are evolving in diverse ways across the State to meet local situations as well as State and Federal guidelines. Together, people are articulating the dream and bringing it to fruition.

This Profile was developed from telephone interviews of 1 to 6 hours duration with contact persons from each of the 40 LICCs. It includes summative statistical data, descriptive information about each local council, and evaluative comments from the 40 respondents. The Profile is intended a) to describe the status of Kansas LICCs as of May 1994, b) to suggest resources for consultation and mentoring among the LICCs, and c) to aid State leaders in supporting the efforts of Kansas communities. Based on the data presented, we offer recommendations for future LICC development.

Although a few LICCs date back to the 1970s, the majority have been formed during the past four years. These groups are in the stage of developing a stable membership and determining their operating procedures. LICCs are highly varied in their geographic range, organization, and degree of responsibility for interagency activities within and beyond Infant-Toddler Services. Many of the older collaborative efforts have assumed a broad responsibility to develop and coordinate services for children and families across a wider age span than the infant-toddler period.

Readers will be impressed by the achievements of the LICCs in a short time. Local dreams are being articulated! Readers will also see the challenges ahead as community groups attempt to wrestle with a) providing comprehensive, coordinated services in a cost-efficient manner to an increasing number of children and families, b) providing families with a range of options while addressing funding limitations, c) honoring existing services while creating new ones, and d) expanding linkages to agencies and services beyond Infant-Toddler Services. As agencies and families "grow together" on their local ICC, these challenges can be addressed most effectively with all responsible parties participating. This Profile describes Kansas efforts to make that happen.

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GROWING TOGETHER: A PROFILE OF LOCAL INTERAGENCY COUNCILS IN KANSAS PLANNING FOR CHILDREN BIRTH THROUGH AGE TWO AND THEIR FAMILIES

...TO ARTICULATE DREAMS

Infants, toddlers, and young children live within a family system of parents, siblings, and extended family members. Families function within a neighborhood, a larger community, the State of Kansas, and the nation. Just as young children and their families differ in many characteristics, so do Kansas communities vary considerably. Each one exemplifies unique resources and needs, ethnic heritages and human histories, various public service networks with both formal and informal configurations, and value systems that are similar to as well as different from those of neighboring farms, towns, and cities.

> *"It is the dream articulated that will shape our communities."*
> *- Lisbeth Vincent*

Kansas planners of Infant-Toddler Services for children with special needs and their families (often called Part H services from the initiating law) recognized this diversity when they called for the establishment of local interagency coordinating councils (see Appendix A). LICCs exist to articulate the dreams of individual communities and nurture them into fruition. Local councils are intended to

- communicate information,
- build relationships, and
- accomplish tasks,

all of which result in comprehensive, coordinated services for community residents. Groups which coordinate the early intervention network of services may serve many additional functions for other local populations as well.

> *"It is important to look at LICC structure and goals individually--by community--and to look at what works rather than with a standardized template...variance is critical!"*

Part H of the Individuals with Disabilities Education Act calls for provision of at least 16 different early intervention services to eligible children from birth through age 2 and their families; these are to be provided "at no cost to families." The diverse needs of these young children and their families may thus require services from many agencies within and beyond the community. The financing of these services may be both complex and costly (Hazel et al., 1988; Kagan, 1991; Melaville & Blank, 1993; Sugarman, 1991; Swan & Morgan, 1993). The opportunities available for child and family support and the costs of providing it differ dramatically across the State. Only interagency collaboration over the long term can eliminate duplication and reduce gaps in services. Building a system of services that truly honors family values and preferences requires that the relevant providers know the families involved and the contexts in which their children are learning and developing. Kansans believe that community people "know their own." Community residents can plan the most effective, cost-efficient, and locally acceptable ways to meet various child and family needs.

In some instances, current efforts at local interagency collaboration for infants and toddlers are being mapped onto previous, less formal multi-agency, cooperative efforts. Coordinating councils go back as far as the mid-1970s in some areas of Kansas. As will be seen below, however, most of the local councils are quite young and still determining their direction and their alliances. In fact, during the six weeks that this report was in preparation, one LICC split into four county groups, and several others redefined their scope and mission.

"We want to expand our council by getting more parents involved and some members of the business community, but everyone has a busy schedule, so it is a continuing process."

PROFILE OF 40 KANSAS LICCS

SOURCE OF THE PROFILE

For some time, local leaders and personnel in state agencies have wished to know more about the nature of local interagency efforts in Kansas communities, especially as they relate to services for children from birth through age 5 and their families. This report is a response to that need.

The Profile was compiled in May 1994 from in-depth interviews with contact persons from each of the 40 Kansas LICCs that were coordinating services for infants and toddlers with special needs and their families. Data were gathered in the following manner:

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1) We telephoned the primary contact person for Infant-Toddler Services grants distributed by the Kansas Department of Health and Environment (KDHE). In some cases, these individuals referred us on to the designated leader of an LICC. Some grantees relate to six or more LICCs. Some areas receiving infant-toddler services are not represented by a formal LICC. At the same time, other counties are included in more than one such group.

"We've gotten off to a real start and just need time to refine everything."

2) After the contact person had scheduled an interview time, a copy of the 12-page interview was mailed for review. For 15 communities, responses were provided by several LICC members or the entire council. In 25 cases, the contact person responded on behalf of the LICC.

3) Telephone interviews occurred with the 40 contact people. These lasted from 1 to 6 hours.

4) Data were entered into a computer program and sorted for summary in the cumulative portions of the Profile.

5) Descriptions of the individual LICCs were generated and mailed to contact persons for editing. Our hope--and theirs--is that these profiles of individual community councils will facilitate sharing among neighboring LICCs.

"We are interested in more information and networking. We are a fledgling group and are open to receiving help from others."

6) Recommendations for future directions were formulated based on information gleaned in the interviews and obtained from a review of the national literature on LICCs. Recommendations presented here reflect the position of the authors.

DEMOGRAPHICS

It is apparent that Infant-Toddler Services and LICCs are related to one another in Kansas but in a variety of ways. Some LICCs exist for the single purpose of providing services to very young children with disabilities and their families. Other LICCs have a broader mission (e.g., services to all children in the community from birth to age 21 as well as their families). Some LICCs receive money directly from Infant-Toddler Services, while others do not. Some hire staff and provide direct services; others are removed from day-to-day issues in early intervention. Many LICCs are closely linked to other interagency efforts in their communities. Other LICCs operate apart from programs such as Corporation for Change Planning Councils and HB 3113 Regional Planning Councils. The data that follow reflect the variety of community approaches in Kansas at this time.

Location: In keeping with Kansas geography, most LICCs are in rural areas: 31 respondents described their area as "mostly rural," while six include a city(ies) of 30,000-100,000 and three contain a city larger than 100,000. This situation is illustrated in Figure 1.

AREAS SERVED BY LICCS

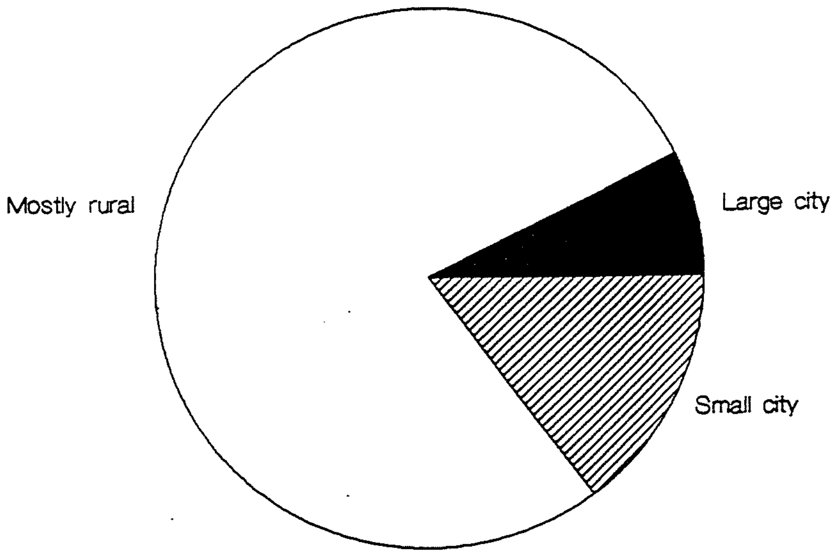

Figure 1

Areas Covered: All but 10 Kansas counties (of 105) have LICCs to oversee Infant-Toddler Services. Gray, Meade, Hodgeman, Clark, and Ness Counties have not yet developed local councils but receive infant-toddler services from Arrowhead West at Dodge City. Rice, Stafford, and Rush Counties have no LICCs; families in these 3 counties receive family service coordination from Sunflower Diversified Services at Great Bend. Clay and Washington Counties have a general Resource Council but receive service coordination from KDHE.

Some LICCs coordinate services for very large geographic areas and some for only a portion of one county. Boundaries for each "community" were chosen by its residents and service providers. In some cases, the boundaries parallel county lines, the area served by a special education cooperative or hospital, or an Indian reservation.

Target Population: Councils vary considerably in whom they serve (see Table 1). Twenty of the 40 LICCs are focused on the birth through 2 age group and their families--17 on children with disabilities only, while three others coordinate services for children at-risk, as well. Eleven councils focus on the birth through 5 age group and their families--two on disabilities only, three on disabilities and at-risk conditions, and six on all children in the age range and their families. Meanwhile, six councils focus on all children birth through 21 years and their families, and one LICC serves all persons with disabilities and their families. Two LICCs have a broader target population; one serves all families and another coordinates all human services in its county. All of the councils with very broad scope are in rural counties. There is a tendency for councils serving birth to 5 or an even greater age range to be in counties with several years of formalized interagency collaboration. It is apparent that the target population for services shapes the mission and activities of each council. The LICCs differ considerably in how they spend their time and in what they produce, as confirmed by the interview data.

Table 1
TARGET POPULATIONS OF LICCS

Children with disabilities B-2 and their families	17
Children at-risk or with disabilities B-2 and their families	3
Children with disabilities B-5 and their families	2
Children at-risk or with disabilities B-5 and their families	3
All children B-5 years and their families	6
All children B-21 years and their families	6
All persons with disabilities and their families	1
All families	1
All persons needing human services	1
Total number of LICCs	40

Relationships with Other Councils: The interagency group that coordinates birth through 2 issues may be related to other interagency efforts in a variety of ways:

- The LICC may be a subgroup of a larger body
- Another interagency group may be a subgroup of the LICC

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- The LICC may have an appointed representative on another council, or vice versa
- The LICC may share members with another body in an informal arrangement that leads to transfer of information
- The LICC and another body may actually be identical (e.g., in one community the Corporation for Change Local Planning Council, the SRS HB 3113 Regional Planning Council, and the Infant-Toddler Services LICC are actually the same group of people meeting one time per month for all purposes).

The cross-State picture of local interagency collaboration that emerges is incredibly complex and, according to our respondents, changing from month to month.

"Before, we had many councils with mostly the same people, but now we have one group. Participation has increased, and the number of meetings has decreased. The new structure has made the group more effective."

During spring 1994, the Infant-Toddler Services LICC was an independent council in 22 communities. It was a subgroup of another interagency committee in 9 of 40 communities and the umbrella group for other workgroups in 4 communities. The birth through 2 council had an appointed representative on another interagency council in 34 of the 40 communities. Six LICCs fulfill dual or triple interagency coordinating roles when the membership meets. These tend to be in rural areas. All of the LICCs polled share some members with other interagency groups. The most likely links are with Special Education Transition Councils, Local Planning Councils (Corporation for Change), and HB 3113 Regional Planning Councils. However, nearby B - 2 LICCs, Regional Drug and Alcohol Prevention Councils, Child and Adolescent Service System Programs, and groups defined locally also received frequent mention.

History: Thirty of the Kansas LICCs have begun since 1990, with 21 forming in 1992 or 1993 (see Figure 2). A few councils are 10-15 years old. These councils are more likely to be the LICCs with a broader mission, although this statement is not true in every case.

Many communities noted informal relationships that predated formal council organization. These relationships have reportedly been useful. However, in instances where the formal council is young, LICCs report major emphasis on the tasks of forming (e.g., determining the membership and establishing operating procedures).

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The youth of many councils is obvious in their responses to questions about pressing issues and challenges. The majority of LICCs are fostering interagency cooperation on rather "safe" issues that build community ownership (e.g., Parent University, needs assessment) and only beginning to define instances for true collaboration in their local areas.

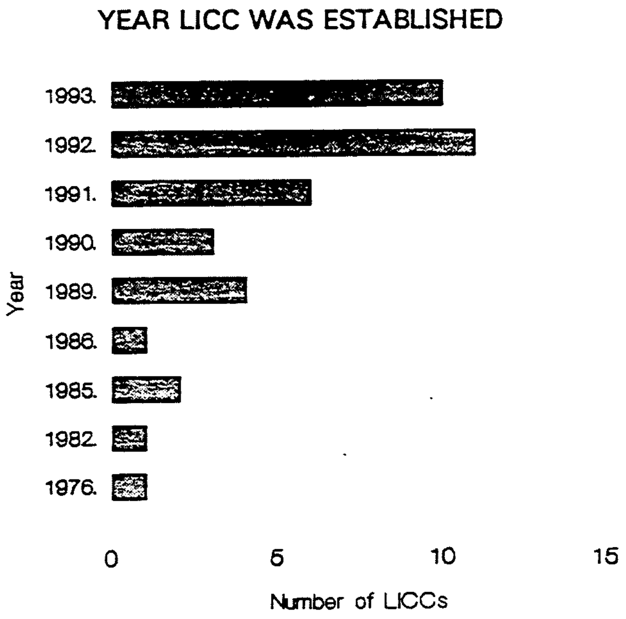

Figure 2

Membership and Attendance: LICCs vary in size from 9-78 members, with a median membership of 27. Typical attendance is significantly less, varying from 4 persons to 32, with median attendance of 14.

Agencies represented on at least half of the LICCs include education, health department, SRS, mental health, and hospital. Parents as Teachers is represented on 31 of the 40 councils, early childhood education on 18, and higher education on 14. Community businesses are represented on 5 of the 40 LICCs.

"If a group becomes too big, it can lose focus."

The data imply a diversity across councils in levels of authority of attendees. Statewide, direct service providers tend to participate more frequently than mid-level administrators, and mid-level agency administrators are reportedly more likely to attend than agency heads. However, this trend may depend upon the size and population of the area served by the LICC: in larger communities, administrators are more likely to attend than personnel who relate directly to families. Twenty-nine of the councils state that a family service coordinator attends regularly; 23 report frequent participation for at least one teacher, and 20 report regular attendance for a therapist.

It is significant for potential collaborative efforts that for the majority of LICCs (33 of 40), members attending the meeting have the authority to commit resources to carry out the council's decisions.

Family Participation: Kansas LICCs "have a way to go" in developing family participation in interagency efforts and consumer input into decision-making. Across the State, parent membership ranges from 0 to 9, with an average of three family members per council. Nevertheless, 25 councils have no parents, or only one, present at 60% of their meetings (see Figure 3).

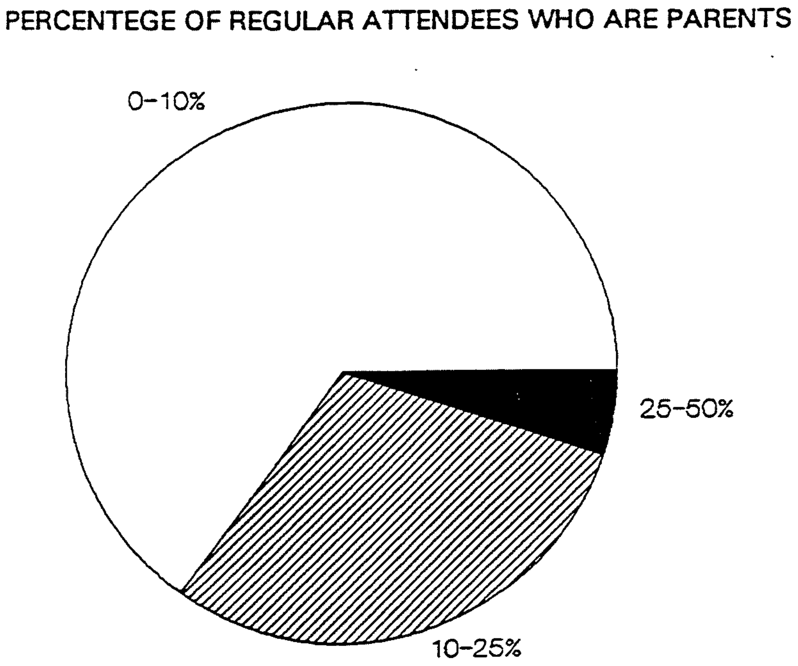

Figure 3

Several strategies are being tried to encourage family participation (see Figure 4). These include providing child care and transportation. Based on interview data, only 18 of the 40 LICCs have arranged their meeting schedule to encourage employed family members to attend; they have been more likely to consider agency representatives' schedules (31 councils) and direct service providers' schedules (24 councils) in choosing meeting times.

ORGANIZATION

Subcommittees: Most LICC business is transacted by the whole council. Nine councils have executive committees that may meet more frequently than the entire LICC. Every community council reported using committees, either on a short-term basis or as a part of the permanent organizational structure. Nineteen different assignments were reported for committee action, most commonly, child

SUPPORT TO FAMILIES TO PARTICIPATE IN LICC

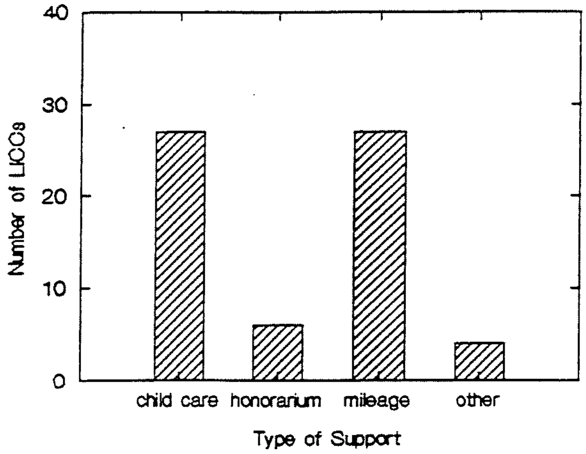

Figure 4

find/screening (17 councils), family issues (11 councils), and service coordination and public awareness (10 councils each).

Paid Staff: Twenty four LICCs report no paid staff. Of the other 16 councils, it is not apparent how many of the staff reported are providing direct services to families (i.e., early intervention personnel) and how many are employed primarily to provide staff support to the LICC.

"It is difficult to know how to use all the people that volunteered--how to coordinate needs with offers to help and relate them to agencies and taskforces. This certainly takes a coordinator, possibly even fulltime."

Funding: Kansas LICCs receive support from a variety of sources (see Figure 5). Thirty-five communities report receiving funds from Infant-Toddler Services through KDHE; these monies may be in the form of LICC minigrants, annual community awards tied to population, or special awards for particular purposes. In more than half of the communities (26 councils), participating agencies donate funds or services to accomplish LICC activities. Other sources of support include Kansas Child Care Training Opportunities (training materials), State and Federal school funds for direct services, and additional costs absorbed by the local lead agency. Respondents listed the following sources of grant funds other than KDHE: Compuplay, Child Care and Development Block Grants, SRS block grants, and homelessness monies.

Governance: Thirty-four of 40 LICCs have a mission statement. These typically are concise statements of a global objective. Examples include

> "Recognizing the child as a member of a family, the LICC will support families, assuring that their child

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with special needs will receive timely and comprehensive services."

"To improve service delivery by creating a set of policies and practices that assure access to services, increase the availability of those services, and enhance the quality of services."

"To further the optimal delivery of comprehensive services to children through coordination, collaboration, and cooperation."

"To provide coordinated prevention, education, and services to support families."

"There are so many different missions represented. It has been necessary to blend these into a multi-agency mission so that everyone felt they were getting something from it."

Thirty-one LICCs have no bylaws to govern their operations; 28 have written interagency agreements or contracts to define, at least to some degree, their working relationships.

Chairs or co-chairs have been designated in 33 of the 40 councils. Most commonly (18 councils) the chair is an agency administrator. Twelve councils have parents as chairs or co- chairs. Most councils rotate their chairs yearly (14), 5 change every 2 years, 1 changes every meeting, and 2 LICCs are chaired by paid staff; 20 councils have not yet decided how long their chairs will serve. Glimpses at LICC operating styles are found in the methods by which chairs are selected. Group consensus is the most common method (15 councils), followed by volunteering (9 councils). More systematized selection procedures in-

FUNDING SOURCES FOR LICC ACTIVITIES

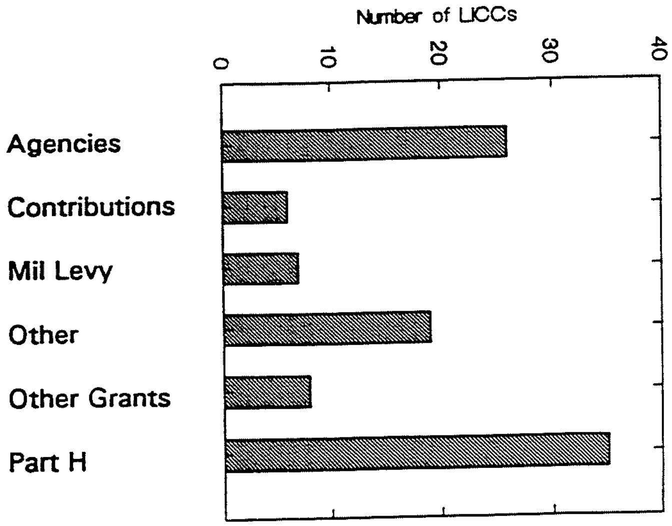

Figure 5

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"It has taken a good year to develop as a group and to be able to give direction and support to our task-forces. The process takes time."

clude election (9 councils) and rotation of responsibility (2 councils).

Meeting Schedules: Fewer than half of the councils meet monthly (16). Six meet bi-monthly, and 15 meet quarterly. Meeting times typically are routine: 37 councils have a regular meeting day, while 36 have a regular meeting time.

Evaluation of LICCs Efforts: Among the older councils, several have conducted formal evaluations to determine satisfaction with quality and quantity of services as well as to locate gaps in services. Most LICCs, however, are relying upon informal feedback or evaluation of a single activity, such as Parent University. Ten councils have not yet considered evaluation.

PRODUCTIVITY

Results of this survey indicate that Kansas LICCs are quite active. Participants frequently express pride in their accomplishments. Figure 6 indicates respondents' estimates of their council's productivity.

Agendas: According to respondents, LICC agendas have been full. Table 2 shows the number of LICCs out of 40 that have included various topics on their agendas during the past year.

Becoming acquainted with one an-

HOW PRODUCTIVE IS YOUR LICC?

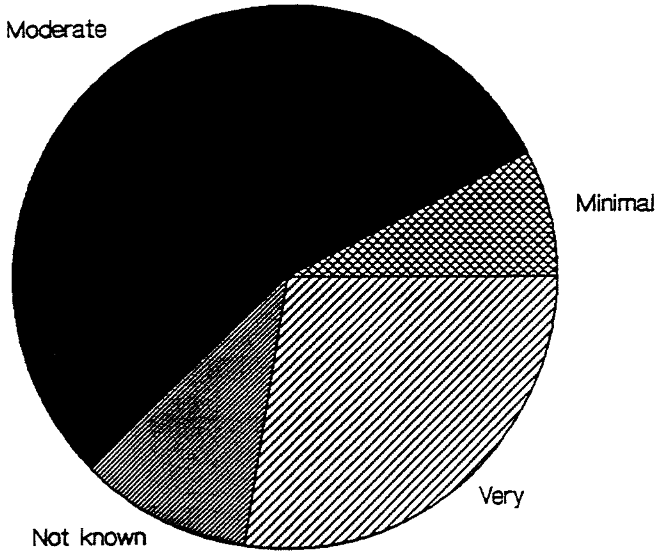

Figure 6

other and information exchange have been the most popular activities, as might be expected especially for newer LICCs. Identification of community needs has been important in establishing council priorities. Similarly, joint public awareness and screening activities have been essential to recruit families for a developing service system. Referral/transition issues are inherently interagency in nature as children and their families move between programs.

Table 2
COUNCIL AGENDA ITEMS DURING THE PAST YEAR

Topic	# of LICCs Discussing
Information exchange	37
Informal networking	36
Identification of community needs	32
Joint public awareness activities	32
Screening and identification	30
Interagency referral/transition procedures	28
Interagency service coordination	28
Eliminating service gaps or duplication	22
Development of grant proposals	22
Joint sponsorship of events	21
Improve evaluations; reduce duplication	20
Advocacy for children and families	18
Development of new services	18
Coordination of parent support	17
Standardized forms to avoid duplication	16
Joint staff development	14
Problem-solving for difficult cases	13
Evaluation of interagency activities	13
Joint annual budgets	13
Development of interagency tracking system	12
Modification of agency policy/procedures	10
Joint funding of personnel/programs	10
Other	5

Products: Products developed by LICCs are summarized in Figure 7. Several, such as a resource directory and a common release of information form, are items likely to make a significant difference for families as well as for service providers in the community. The last section of this report, which profiles individual LICCs, describes the accomplishments of each local council. Most respondents express willingness to share

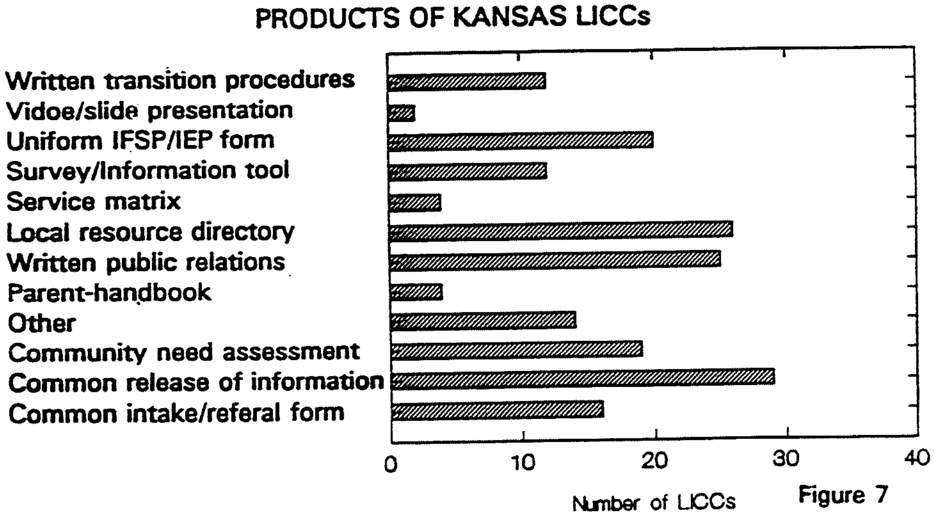

Figure 7

2-49

HOW SATISFIED ARE YOU WITH YOUR COUNCIL'S PROGRESS?

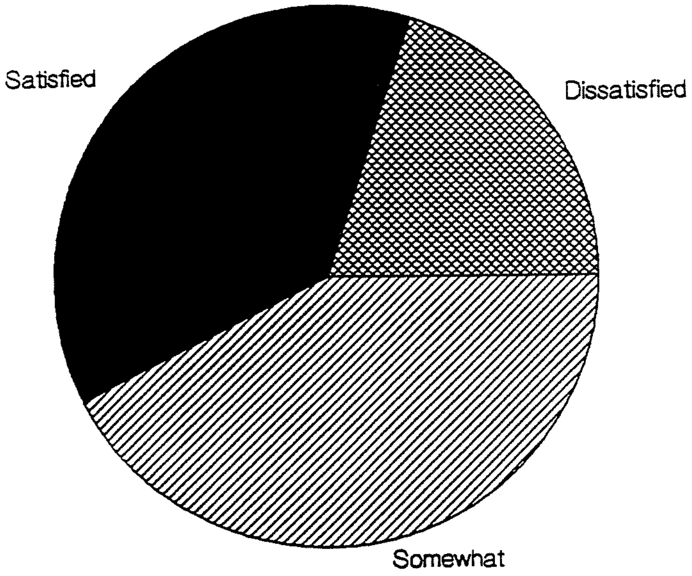

Figure 8

their products with other LICCs, either directly or via the Bridging Early Services Transition Project office.

Satisfaction with Progress: Respondents frequently commented on their high aims for their LICC. They also regularly noted the challenges of developing and sustaining interest, agreeing upon operating procedures, and accomplishing tasks given limited money and time. In spite of these common obstacles, most respondents, as seen in Figure 8, are at least somewhat satisfied with the recent progress of their council, and many are highly satisfied. Forming and nurturing the group has been a victory for some of the newer councils, while more established ones have myriad accomplishments to their credit (see Individual LICC Profiles).

"There is a continuing lack of knowledge and understanding--even among professionals--as to Part H and its purpose, and that is a challenge."

Continuing barriers to achievement revolve around two issues:

- the need to orient all LICC members to the purpose, underlying laws, and interagency nature of council activities so they can move forward together, and
- the process of change from the way(s) services were accomplished previously to how they are to be delivered now

"We have concern about 'taking over' in situations where services and relationships are already established."

Other common issues are shortage of money and time to accomplish goals, difficulties in communicating, differences in philosophies and missions among agencies, and turfism. One comment foreshadowed an issue which may lie ahead for some councils as they move beyond the intital stages of "forming" and "norming": "we are afraid to address the issue of cost effectiveness or duplication of services because it might offend."

"How do you build a new system without destroying the old system?"

TRAINING NEEDS

Because interagency collaboration tends to be difficult and because few service providers or parents have been formally trained to do it, many LICCs would like to receive training to help them progress faster. There appear to be strong preferences about the location and topics for training.

"We could use training in collaboration."

Location: Respondents clearly want training delivered close to home. 65% prefer local workshops to regional training or statewide conferences. 50% would like to receive technical assistance locally, that is, on-site action planning for council development. One third wish to see a mentor program whereby more experienced LICCs assist their neighboring councils. Mentoring appears to be possible, since most contact persons said they would be happy to share the results of their work to date. An LICC newsletter is desired by half of the respondents, and the establishment of a resource library with LICC-related publications is favored by one-fourth. Teleconferences are controversial: some groups prefer them, while others noted their dislike for this medium.

Time for Training: As shown in Figure 9, there was no consensus concerning the best time for training. State leaders, professional organizations, and grant projects interested in planning training and technical assistance to LICCs must provide a menu of options if they wish to meet local needs.

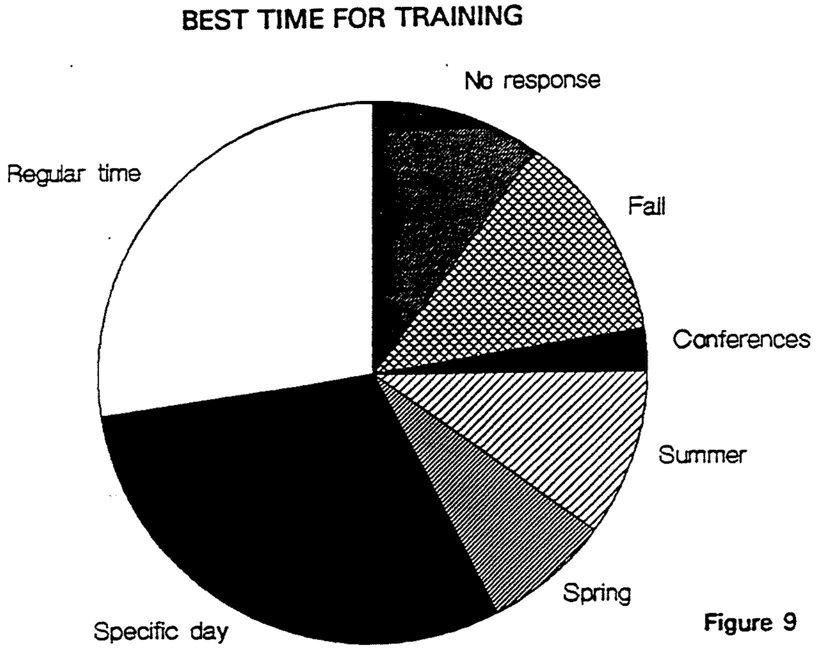

Figure 9

"The kinks are not yet worked out for smooth operation."

Training for Council Leaders: Two topics were favored by more than half of the respondents: how to bring important players to the table and strategic planning. Approximately one-fourth of the LICCs would like leadership training on the following topics: methods to disseminate information, group process, and conducting a meeting. Little interest was expressed in training in conflict resolution. Perhaps this is due to the relative youth of most councils and the fact that most projects undertaken in the early stages of council formation have had broad consensus from their local councils. Several older LICCs, however, commented about "turfism" and the desire for something better: "We need training in collaboration; we have a long history of cooperation."

"It is important to learn more about how we can collaborate and share resources and provide services--but time is a barrier."

Training for LICC Members: Half of LICCs wish to receive training in basics of local council operation: local mission, relevant laws, and services and programs provided by a variety of agencies. Approximately one-fourth of LICCs say they would appreciate training in group process and problem-solving skills. Other topics requested include effective transition practices, conflict resolution, and strategic planning. Several respondents expressed the wish that state agencies would train their local personnel about Part H of P.L. 102-119 and Kansas Infant-Toddler Services. The purpose of such training would be to see how the agency's mission meshes with birth through 2 services for children with special needs and their families. A common request of respondents was for access to outside facilitators who can help LICCs work through their needs assessment and strategic planning.

LOOKING TO THE FUTURE

Comments about future priorities reflect the councils' twin concerns of relationship building and task accomplishment. Many are aware of the need to build their new and fragile coalition and to formalize its operations with bylaws and formal links to other councils. Other communities have defined specific, one-time, highly visible projects with which all agencies can identify (e.g., Parent Universities, media campaign, needs assessment, transition guidelines, and hiring an interpreter to serve all agencies). A few councils have worked on such tasks for several years and are now wondering how to move from cooperation to collaboration and how to resolve sticky issues such as responsibilities of lead and fiscal agencies, cost-effectiveness of services, the expansion of requests for services without accompanying expansion of funds, and the recruitment of needed personnel to rural areas. A number of councils expressed concerns about monitoring by KDHE related to Part H and how that will affect their LICC's operations, while others welcomed the new monitoring approach as a guide to support their LICC development.

"We need to learn to think globally—to move from Part H to B-21 in mission."

INDIVIDUAL LICC PROFILES

The community profiles later in this book were compiled from interview data and forwarded to community contact persons for editing. They are intended to stimulate new directions in collaboration for local councils, to encourage sharing and mentoring among LICCs, and to illustrate the diversity and local creativity which currently characterize Kansas LICCs.

DISCUSSION AND RECOMMENDATIONS

The Profile confirms two important findings:
* a great deal has been accomplished in a short time in Kansas communities due to interagency efforts
* many more local activities are currently underway

"More and more of our members are thinking <u>wrap around</u> and <u>year around</u> services."

These facts are cause for celebration! They also suggest the need for ongoing nurturance of infant councils once participants' initial goals have been met.

The leaders who outlined the Kansas Infant Toddler Services system insisted that communities must have a right to define themselves and to develop locally appropriate services for infants and toddlers with special needs and their families. This report is evidence that the anticipated local efforts are building. We see in Kansas at this time a surprising diversity in approaches to interagency collaboration at the local level. Several respondents raised questions about the future, with some favoring increasing systematization just as an equal number specifically rejected it.

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As LICCs affiliated with Infant-Toddler Services and those affiliated with other state initiatives mature, the authors of this report hope that they will grow toward one another--sharing information, service strategies, and scarce resources to an even greater degree than is seen at present. There is evidence of this trend in the data presented here, especially for rural areas.

We hope that the interview process helped at least some LICCs to be more reflective about themselves and their functioning. We hope that this Profile will serve as a first step in helping LICCs locate mentors in other communities who have dealt with similar organizational and content issues. Finally, we hope it will aid and encourage the sharing of products and processes which have been shown to be effective. The Profile will need to be updated periodically, given the fluid nature of Kansas interagency collaboration at this time. Following are some additional recommendations which reflect opinions of the Profile's authors but not necessarily those of KDHE:

"I saw a bumper sticker that said: 'Think globally; act locally.' That's what we're trying to do."

FOR COMMUNITIES

1) Continue to encourage family members to participate in LICCs and provide incentives for them to do so. Scheduling meetings at a time of day when families can attend would likely help LICCs to boost family involvement. Intentionally looking at every issue from a family perspective will enrich the council's contributions and help family participants feel that their time is well spent. Individual or small group activities may also help family members feel comfortable participating. Involvement with subcommittee projects and the development of products useful to parents may help family members sense that their efforts are beneficial for other families.

2) Consider whether additional members should be recruited for the LICC. We are concerned about the small reported participation by community early childhood professionals, business persons, church and recreation leaders, and hospitals. Representatives from these organizations should be part of a community's early intervention network. Careful orientation to both the LICC and Kansas Infant

2-54

Toddler Services, followed by involvement in a particular meaningful project, may help significant community leaders to develop long-term commitment to LICC efforts.

3) Link with other interagency efforts whenever possible to reduce redundancy in meeting time, diminish competitiveness among agencies or councils, and strengthen community commitment to children and families.

"Comments from family members continually remind us why we're here."

4) Orient every new member to the LICC's mission statement and operating procedures in order to develop a cohesive council that truly shares a joint purpose. Defined responsibilities and procedures for orientation wil help this important task to occur. Ensure that every LICC member receives It's News and other relevant newsletters and is encouraged to read them.

5) Actively seek ways to help multiple agencies, families, and the business community "own" projects.

6) Keep good records of what you do, and eventually write down, evaluate, and refine the informal operating procedures that are guiding your council. Determine how to streamline the handling of routine matters in order to leave time to address newer, more important issues.

7) Conduct strategic planning based upon the needs of the community. Request recommendations from KDHE for an outside facilitator if that would be useful.

"We need to look at services in terms of natural environments for children. Parents as Teachers helps us do that."

8) Invite state early childhood personnel from KDHE, KSBE, SRS, and/or the Coordinating Council on Early Childhood Developmental Services to attend a meeting of your council. They will learn from you just as the LICC can learn from them.

9) Send representatives to meetings of the state Advisory Committee to the Coordinating Council. These quarterly events provide an excellent opportunity to network with other LICCs.

10) Create a climate where disagreement can be expressed honestly and openly -- but without personal

2-55

animosity. View conflict as an opportunity to develop greater understanding of various perspectives in the community and to initiate creative new ways to attack familiar problems.

"We had some rough times for awhile, but now we're stronger for having talked it all out."

9) Maintain the focus on children and families, even as increasing time is spent on policies and procedures.

10) Systematically evaluate what you do. Report that information to the community, to state agencies, and to other LICCs. Use evaluative data to improve community services.

11) Nurture relationships, and celebrate successes!

FOR STATE AGENCIES AND THE COORDINATING COUNCIL FOR EARLY CHILDHOOD DEVELOPMENTAL SERVICES

1) Develop a Make a Difference newsletter which periodically shares information about effective interagency strategies.

2) Include such suggestions in <u>It's News</u>, the Corporation for Change newsletter, <u>KITS' newsletter</u>, and professional organizations' mailings, making certain that every member of local councils has access to significant newsletters.

"I see the potential of our group and think it's wonderful! All the members see the LICC as a positive thing."

3) Develop a technical assistance and peer mentoring system for LICCs that honors participants' time and travel constraints.

4) Continue to encourage LICCs which are focused on birth through 2 to link with other interagency councils, as locally appropriate.

5) Publicize the LICC system which is developing, and strengthen its links to the State Coordinating Council.

6) Provide leadership training for LICC officers who wish to receive it; perhaps audio or videotapes can be used to minimize travel and increase availability.

2-56

7) Arrange for an ongoing repository for LICC products that can be shared across councils. In the short term, this function will be filled by the Bridging Early Services Transition Project at ACCK, McPherson.

8) Send state agency representatives, when invited, to LICC meetings to applaud local accomplishments, aid in problem solving, clarify misconceptions, and visibly represent state commitment to local interagency efforts.

"I have great hope for our LICC. We can do so much more for families when we plan together."

9) Urge LICCs to share their needs and accomplishments on a regular basis with one another through the Advisory Council, with state leaders, and with the Coordinating Council.

10) Continue to articulate support by the secretaries of state agencies (KDHE, Education, and SRS) for participation by their local counterparts in LICC planning. It seems timely to repeat the jointly signed letter urging such participation that was sent in 1991 by the three department secretaries who sit on the Coordinating Council.

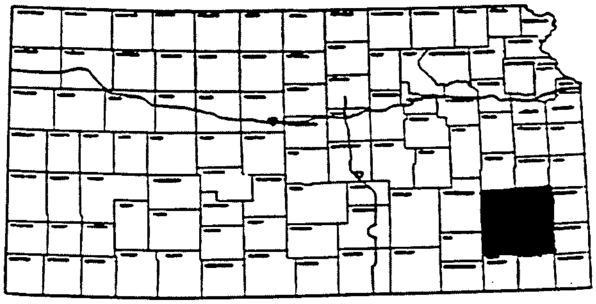
10) Nurture relationships, and celebrate successes!

2-57

ALLEN, NEOSHO, WOODSON, AND WILSON COUNTIES

THIS COUNCIL IS REORGANIZING INTO FOUR SEPARATE COUNTY COUNCILS. CONTACT PATTY HASTY FOR INFORMATION ABOUT THE NEW COUNCILS.

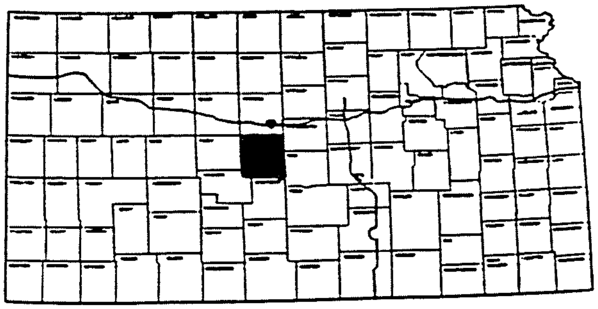
ANW Interagency Coordinating Council
Contact: Patty Hasty
2601 Gabriel
Parsons, KS 67357
(800) 362-0390 Ext. 1859
FAX (316) 412-6550 Ext 1702



TARGET POPULATION	Children with disabilities 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	LICC and HB 3113 Regional Planning Council are the same entity
YEAR ESTABLISHED	1990
FUNDING OF COUNCIL ACTIVITIES	Part H mini grant; agencies share costs
MEETING SCHEDULE	Quarterly: 3rd Tuesday, 11:30 - 1:00 p.m.
PURPOSE	To seek agencies dedicated to providing services to children and their families
CURRENT GOALS	To provide two Parent Universities involving four LICCs
ACCOMPLISHMENTS	Three Parent Universities with 2 more planned for spring, involving four LICCs
WRITTEN PRODUCTS	Local resource directory and common release of information form are available from LICC or BEST project

2-58

BARTON COUNTY



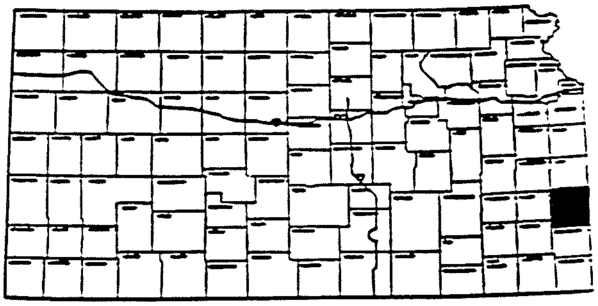
Barton Early Awakenings Interagency Coordinating Council
Contact: Jane Meschberger
Sunflower Diversified Services, Inc
Sunflower Early Education Center
1312 Patton Road
Great Bend, KS 67530
(316) 792-4087
FAX (316) 792-4709

TARGET POPULATION	Children at-risk or with disabilities 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with LICCs in nearby areas, Local Planning Council. Appointed representative on the LICC from HB 3113 Regional Planning Council
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Monthly: Tuesday, lunch
PURPOSE	To identify children with special needs; make services available; make parents aware
CURRENT GOALS	None
ACCOMPLISHMENTS	Monthly community screenings; bibs for Healthy Start visitors; gifts for newborns
WRITTEN PRODUCTS	Local resource directory, brochure, and screening summary sheet for joint screening for parents and agencies are available from LICC contact or BEST Project

2-59

BOURBON COUNTY

Bourbon County Interagency Coalition
Contact: Rev. Charles Baker
or Marty Schmidt
123 Scott
Fort Scott, KS 66701
(316) 223-3080

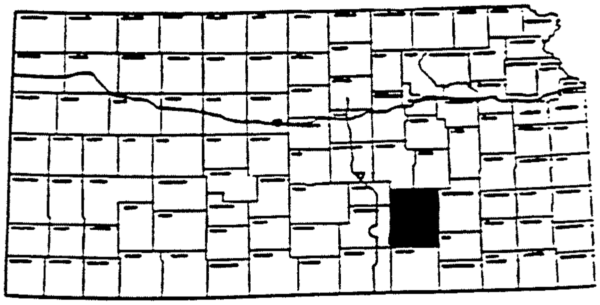


TARGET POPULATION	Children with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	The LICC and the County Coalition are the same entity
YEAR ESTABLISHED	1993
FUNDING OF COUNCIL ACTIVITIES	Agencies share costs
MEETING SCHEDULE	Monthly: 1st Wednesday, 12:00 - 1:00 p.m.
PURPOSE	To offer a coordinated effort of various organizations/agencies for the delivery of multi-leveled specialized services to children and families in Bourbon County
CURRENT GOALS	To continue greater cooperation; continued practice of assisting children and their families
ACCOMPLISHMENTS	Multidisciplinary Team; formation of a Board of Directors; and seeking incorporation
WRITTEN PRODUCTS	Local resource directory, common intake or referral form, common release of information form, and written procedures for referral and/or transition are available from LICC or BEST project

2-60

BUTLER COUNTY

Butler County Interagency
Coordinating Council
Contact: Kathy Donovan
924 N. Topeka B-1
El Dorado, KS 67042
(316) 321-3274
FAX (316) 321-3087

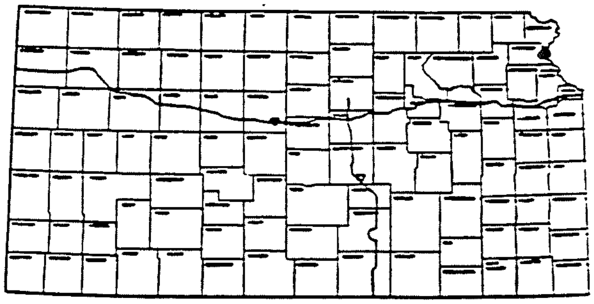


TARGET POPULATION	Children at-risk or with disabilities 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	None
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Quarterly
PURPOSE	To maintain a multi-disciplinary team and insure that a comprehensive system of integrated services is available in Butler County for its children from 0-5 who are at-risk of developmental delays and their families
CURRENT GOALS	To train and educate personnel to assist in successful transitions to Part B services
ACCOMPLISHMENTS	Directed services to families in the county not previously served
WRITTEN PRODUCTS	Local resource directory, common intake or referral form, common release of information form, and uniform IFSP/IEP forms are available from LICC or contact BEST Project

2-61

CITY OF ATCHINSON

"The Dream Team" Interagency
Coordinating Council
Contact: Mike Hughes
Atchinson Public Schools, USD 409
605 Kansas Avenue
Atchinson, KS 66002
(913) 367-4384
FAX (913) 367-2246

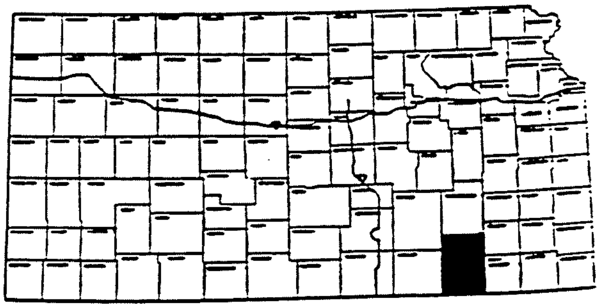


TARGET POPULATION	All children 0-21 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Appointed representative on local committee of Regional Drug and Alcohol Prevention Council
YEAR ESTABLISHED	1992-1993
FUNDING OF COUNCIL ACTIVITIES	Local contributions; agencies share costs
MEETING SCHEDULE	Monthly: 1st Monday, 12:00 noon
PURPOSE	To coordinate services for children and families
CURRENT GOALS	To focus on community involvement in three issues (fight domestic violence, child abuse, and crime); develop funding from drug free school grants and other sources; develop a coordinated approach without duplicating efforts
ACCOMPLISHMENTS	Promotion of community awareness activities; coordination of services
WRITTEN PRODUCTS	Local resource directory available from LICC contact or BEST Project

2-62

CHAUTAUQUA AND ELK COUNTIES

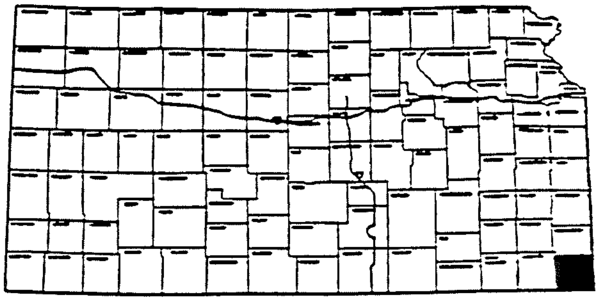
Chautauqua and Elk County
Interagency Coordinating Council
Contact: Bert Moore
Special Education Services
Cooperative
PO Box 607
Howard, KS 67349
(316) 374-2113
1-800-498-2003
FAX (316) 374-2414



TARGET POPULATION	All children 0-21 years and their families
AFFILIATIONS WITH OTHER COUNCILS	LICC shares members with HB 3113 Regional Planning Council, Special Education Transition Council, Child Protection Team of Chautauqua County
YEAR ESTABLISHED	1991
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Monthly
PURPOSE	To facilitate the education of children birth through 21
CURRENT GOALS	To accomplish interagency cooperation and collaboration
ACCOMPLISHMENTS	The Wrap Around grant; implementation of Part H; a common release form and formal Interagency Agreements
WRITTEN PRODUCTS	Local matrix directory, common release of information, uniform IFSP/IEP form, written procedures for referral and/or transition, and parent guide are available from LICC contact or BEST Project

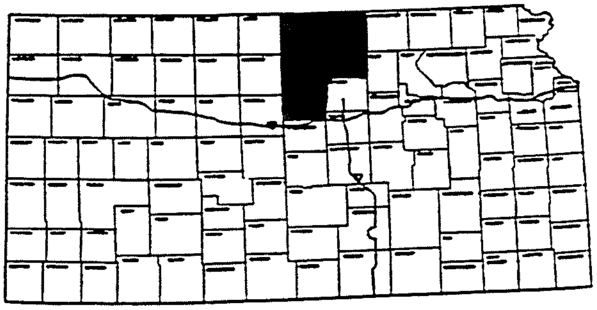
CHEROKEE COUNTY

Cherokee County Early
Intervention Team
Contact: Darlene Montgomery
702 East 7th
Galena, KS 66739
(316) 783-2332
FAX (316) 783-5547



TARGET POPULATION	Children with disabilities 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	LICC is a subgroup of County Coalition
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL ACTIVITIES	Part H funds; Part H mini grants; agencies share costs
MEETING SCHEDULE	Quarterly: 4th Wednesday, 1:00 - 3:00 p.m.
PURPOSE	To seek agencies dedicated to providing services to children and their families
CURRENT GOALS	To provide two Parent Universities for spring, involving four LICCs; hold resource fairs; provide parenting classes
ACCOMPLISHMENTS	Three Parent Universities, with 2 more planned, involving four LICCs; Resource Fairs at WIC sites
WRITTEN PRODUCTS	Local resource directory, common release of information form, and brochure are available from LICC contact or BEST Project

CLOUD, LINCOLN, MITCHELL, JEWELL, REPUBLIC COUNTIES



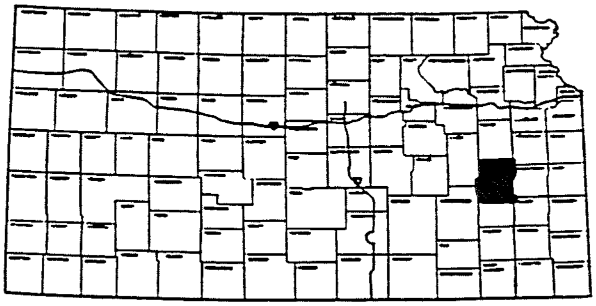
North Kansas Disabilities Council
Contact: Leslie Hemphill
1010 3rd Avenue
Concordia, KS 66901
(913) 243-1233

TARGET POPULATION	Children with disabilities 0-5 years and their families; presently focusing on 0-3
AFFILIATIONS WITH OTHER COUNCILS	LICC has an appointed representative on HB 3113 Regional Planning Council. LICC shares members with local committee of Regional Drug and Alcohol Prevention Council and Community Resource Council
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL ACTIVITIES	Part H funds; county mill levy; SRS; private insurance
MEETING SCHEDULE	Quarterly: 1st Monday, 7:30 p.m.
PURPOSE	To provide services to infants and toddlers 0-5 with disabilities
CURRENT GOALS	To expand services to Lincoln, Jewell, and Mitchell counties; to prepare grant proposals for parents of infants, including those with developmental delays
ACCOMPLISHMENTS	Providing services
WRITTEN PRODUCTS	Common release of information, uniform IFSP/IEP form, expense forms for providers, order forms for products are available from LICC contact or BEST Project

2-65

COFFEY COUNTY

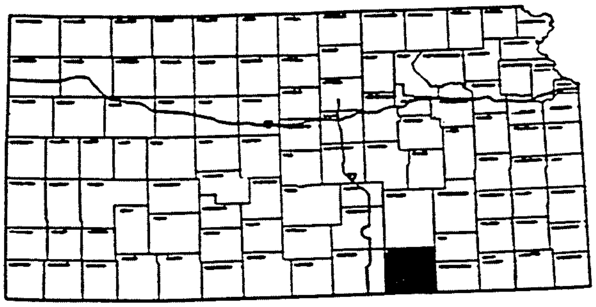
Coffey County Interagency
Coordinating Council
Contact: Derald Hurt
200 South Sixth
Burlington, KS 66839
(316) 364-5151
FAX (316) 364-8548



TARGET POPULATION	All persons with disabilities and their families
AFFILIATIONS WITH OTHER COUNCILS	LICC is a subgroup of Local Planning Council, HB 3113 Regional Planning Council. The following are subgroups of the LICC: Special Education Transition Council, Local committee of Regional Drug and Alcohol Prevention Council
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL ACTIVITIES	Part H Funds; local contributions; agencies share costs
MEETING SCHEDULE	Monthly: 3rd Wednesday, 12:00 noon
PURPOSE	To strengthen the ties between agencies, increase awareness of direct service providers, and develop a working model of interagency collaboration
CURRENT GOALS	To activate the Child Protection Team and recruit law enforcement participation
ACCOMPLISHMENTS	Incorporating HB 3113; collaborating/cooperation in implementing and developing it with From Day One; Multi-disciplinary Child Protection Team; Targeting birth-21 for disabilities; emphasizing birth-death for our scope
WRITTEN PRODUCTS	Common release of information form, uniform IFSP or IEP forms, and goal statement available from LICC or BEST Project

COWLEY COUNTY

REACH Interagency Coordinating Council
Contact: Phil D. Rust
1320 North McCabe
Winfield, KS 67156
(316) 221-1200, Ext. 341
FAX (316) 221-1756

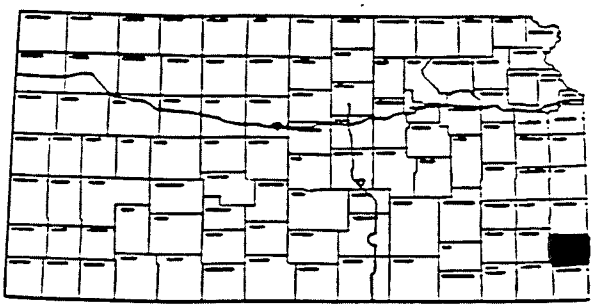


TARGET POPULATION	Children with disabilities 0-3 years and their families; at-risk.
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with other interagency groups, including Parents as Teachers, Southwestern College Social Work Advisory Board, CHIC
YEAR ESTABLISHED	1982
FUNDING OF COUNCIL ACTIVITIES	Part H funds; county mill levy; local contributions; United Way; agencies share costs; Chapter I; categorical aid from Kansas State Board of Education
MEETING SCHEDULE	Quarterly: Thursday, noon
PURPOSE	To provide an advisory board to REACH, approve its goals and projects, serve as good advocates for the REACH program
CURRENT GOALS	To maintain funding, an on-going challenge
ACCOMPLISHMENTS	Getting mill levy passed for funding, 1990 (LICC will share information about strategies)
WRITTEN PRODUCTS	Local resource directory (part of a community one), common intake or referral form, common release of information form, brochure, poster, other written public relations items, video/slide presentation, written procedures for referral and/or transition, surveys and other information tools are available from LICC contact or BEST Project

2-67

CRAWFORD COUNTY

Crawford County Interagency
Coordinating Council
Contact: David Lindeman
2601 Gabriel
Parsons, KS 67357
(316) 421-6550 Ext-1859
FAX (316) 421-6550 Ext. 1702

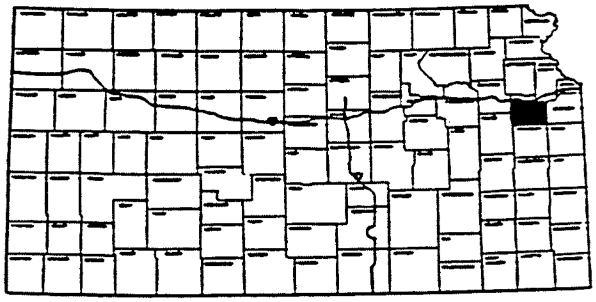


TARGET POPULATION	Children with disabilities 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	County coalition
YEAR ESTABLISHED	1990
FUNDING OF COUNCIL ACTIVITIES	Part H mini grants; agencies share costs
MEETING SCHEDULE	Quarterly: 2nd Wednesday, noon
PURPOSE	Dedicated to improving services for children and families
CURRENT GOALS	To assist in planning second Parent University in fall
ACCOMPLISHMENTS	Monthly ICC Child Find Clinics; One Parent University; donation for Families Together Enrichment Weekend
WRITTEN PRODUCTS	Local resource directory, common release of information form, and brochure are available from LICC contact or BEST Project

2-68

DOUGLAS COUNTY

Lawrence/Douglas County
Infant/Toddler Coordinating Council
Contact: Sarah Ailor
1837 Vermont
Lawrence, KS 66044
(913) 832-5650
FAX (913) 864-5323

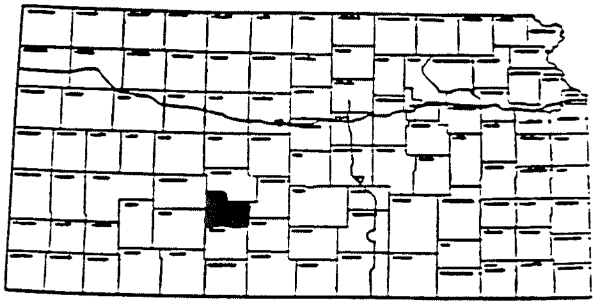


TARGET POPULATION	Children with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER ACTIVITIES	Shares membership with HB 3113 Regional Planning Council, Special Education Transition Council, Local Planning Council, CASSP Council, LICCs in nearby areas, Local Committee of Regional Drug and Alcohol Prevention Council
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL ACTIVITIES	Part H funds; Chapter I funds
MEETING SCHEDULE	Monthly: 3rd Thursday, 9:00 a.m.
PURPOSE	To develop a comprehensive service delivery and support system for all children and families in the Douglas County area, with special emphasis on young children who have special needs and their families; to promote coordination of service through development of a network of service providers, parents, and others in the community
CURRENT GOALS	To smooth transitions from Part H to Part B; promote inclusion; get IFSPs in place; refine evaluation and screening procedures; identify a new fiscal agent
ACCOMPLISHMENTS	Service providers know each other; putting IFSPs in place
WRITTEN PRODUCTS	Local resource directory, common intake or referral form, common release of information, uniform IFSP forms, brochure, written procedures for referral and/or transition, and surveys are available from LICC contact or BEST Project

2-69

EDWARDS COUNTY

TASK Interagency Coordinating Council
(Team Association Serving Kids, Inc.)
Contact: Gerri Stegman
Edwards County Health Department
Box 99
Kinsley, KS 67547
(316) 659-3102
FAX (316) 659-3621-Ask to be transferred
to the FAX

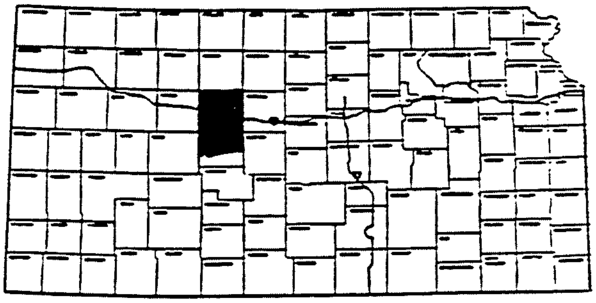


TARGET POPULATION	All children 0-21 years and their families
AFFILIATIONS WITH OTHER COUNCILS	None
YEAR ESTABLISHED	1991
FUNDING OF COUNCIL ACTIVITIES	Part H funds; local contributions; agencies share costs
MEETING SCHEDULE	Quarterly: 2nd Monday of the quarter, 3:30 p.m.
PURPOSE	To network and eliminate duplication of services
CURRENT GOALS	To continue with present projects and address new issues as they appear
ACCOMPLISHMENTS	Parent book for new parents to be given at hospital; a children's health fair every year; a latch key kids program; networking to do the above (LICC will share information on these topics)
WRITTEN PRODUCTS	Local resource directory, common intake or referral form, common release of information form (in progress), uniform IFSP or IEP forms, brochure, poster, other written public relations items, written procedures for referral and/or transition, parent handbook, and information tools are available from LICC contact or BEST Project

2-70

ELLIS COUNTY AND PART OF RUSH COUNTY

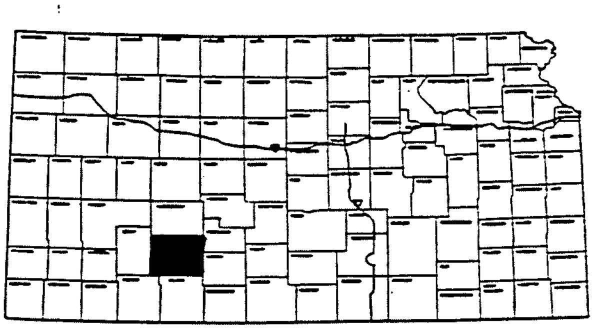
Hays Interagency Coordinating
Council
Contact: Leila Montoia
94 Lewis Drive
Hays, KS 67601
(913) 625-3257



TARGET POPULATION	All children 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Share respresentative with HB 3113 Regional Planning Council, Special Education Transition Council, LICCs in nearby areas
YEAR ESTABLISHED	1976 "Standards" were adopted; previous history from 1966 informally (college & ARC)
FUNDING OF COUNCIL ACTIVITIES	Part H funds; county mill levy; local contributions; grants
MEETING SCHEDULE	Quarterly; 3rd Wednesday, 3:00 p.m.
PURPOSE	To further optimal delivery of comprehensive services to children through coordination, collaboration and cooperation
CURRENT GOALS	To participate in "Pilot Monitoring" through Topeka, Part H and write new grant proposals when Requests for Proposals come out
ACCOMPLISHMENTS	Written "Standards"; brochures for the community; monthly screenings (LICC will share information)
WRITTEN PRODUCTS	Brochure, written public relations items, and written procedures for referral and/or transition are available from LICC contact or BEST Project

FORD COUNTY

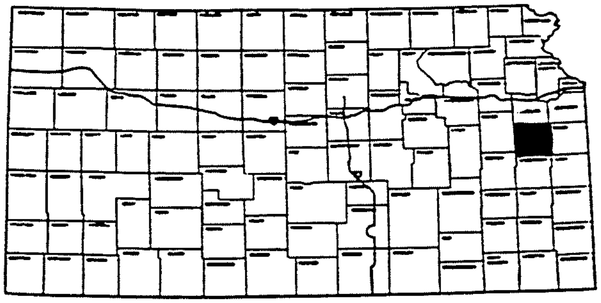
Ford County Interagency
Coordinating Council
Contact: Jane Cooper
We Care Child Care Center
210 Soule Street
Dodge City, KS 67801
(316) 227-8181
FAX (316) 227-8181



TARGET POPULATION	All children 0-21 years and their families
AFFILIATIONS WITH OTHER COUNCILS	LICC is a subgroup of Local Planning Council (Corporation for Change)
YEAR ESTABLISHED	1991 - LICC. In 1979 had an interagency council working on screenings.
FUNDING OF COUNCIL ACTIVITIES	Part H mini-grants; local contributions; agencies share costs
MEETING SCHEDULE	Bi-monthly: 2nd Wednesday, Noon
PURPOSE	To provide screening clinics; implement Kansas Blueprint to meet community needs; eliminate duplication of services
CURRENT GOALS	To obtain funds for coordinator who will become the one central contact person for Ford County; to implement Kansas Blueprint
ACCOMPLISHMENTS	Networking; resource directory; screening clinic; implementing the Kansas Blueprint. A strong legislative committee on the Council has been effective on keeping up to date on children's issues (LICC will share information)
WRITTEN PRODUCTS	Local resource directory, uniform IFSP/IEP forms, and written procedures for referral and/or transition are available from LICC contact or BEST Project

FRANKLIN COUNTY

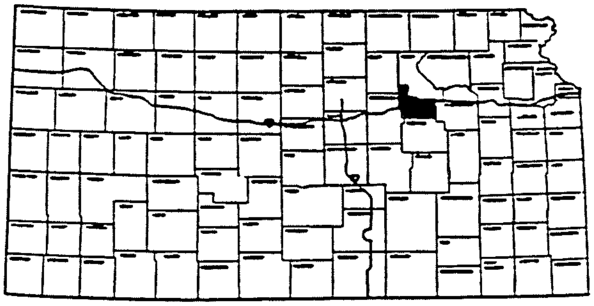
Ottawa-Wellsville Early
Childhood Coordinating Council
Contact: Carolyn Newmaster
420 South Main
Ottawa, KS 66067
(913) 242-3818
FAX (913) 242-5832



TARGET POPULATION	Children with disabilities 0-5 years and their families
AFFILIATIONS WITH OTHER COPUNCILS	NONE
YEAR ESTABLISHED	1993
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs; KSBE categorical reimbursement
MEETING SCHEDULE	Monthly: 3rd Tuesday, 7:00 p.m.
PURPOSE	To improve coordination so that families are not shuffled but served through a central point with appropriate assistance
CURRENT GOALS	To collect information gathered and develop a common intake form, conduct a needs assessment, and learn what each agency has to offer
ACCOMPLISHMENTS	Pulling together; focusing on services; able to get the grant money to employ a family services coordinator
WRITTEN PRODUCTS	Common intake or referral form, common release of information form, uniform IFSP or IEP forms, and brochure

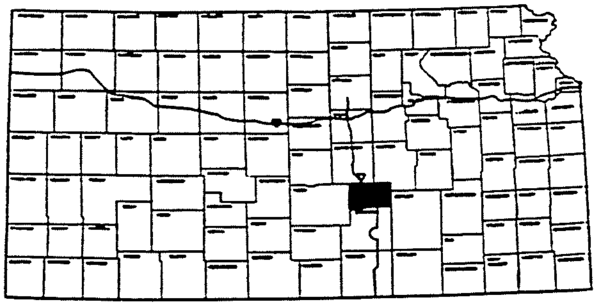
GEARY COUNTY

Geary County Interagency
Coordinating Council
Contact: Maggie Davidson
Pawnee Mental Health Services
814 Carolyn Avenue
Junction City, KS 66441
(913) 764-5250



TARGET POPULATION	Children with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with HB 3113 Regional Planning Council, Special Education Transition Council
YEAR ESTABLISHED	1993
FUNDING OF COUNCIL ACTIVITIES	Part H funds
MEETING SCHEDULE	Monthly: Thursday, 12:00 Noon
PURPOSE	To assist young children with special developmental needs age B-2 to progress to maximum abilities through identification and early intervention
CURRENT GOALS	To increase parent awareness; identify direct service providers; improve transportation; and resolve Champus issues
ACCOMPLISHMENTS	Writing the grant; hiring a service coordinator; identifying the fiscal and lead agent; implementing a program; and providing services
WRITTEN PRODUCTS	Local resource directory, service matrix, common intake or referral form, common release of information, uniform IFSP forms, brochure, written procedures for referral and/or transition, data collecting form for reports, and evaluation form for providers are available from LICC contact or BEST Project

HARVEY COUNTY



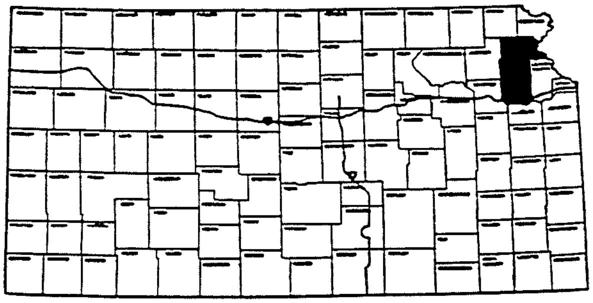
Harvey County Early Intervention
Interagency Council
Contact: Wayne Schon
725 Main
Newton, KS 67114
(913) 284-6580
FAX (316)284-6207

TARGET POPULATION	Children with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with HB 3113 Regional Planning Council; Special Education Transition Council; Parents' University Coordinating Council
YEAR ESTABLISHED	1993; school and developmental disabilities center provided services since 1980
FUNDING OF COUNCIL ACTIVITIES	Part H funds; local contributions; district assessments through the Harvey County Special Education Cooperative; categorical aid from the Kansas State Board of Education
MEETING SCHEDULE	Quarterly: Friday, 11:00 a.m.
PURPOSE	To form interagency council with parent participation, increase publicity of services, increase number of service providers, co-sponsor an open house at hospital with Parents as Teachers, provide summer programming, and develop a resource guide for parents of children birth-3
CURRENT GOALS	To increase our family service coordination staff; expand our summer programming
ACCOMPLISHMENTS	Getting the council formed; writing the grant (LICC will share information on these topics)
WRITTEN PRODUCTS	Local resource directory (Child Find Resource Book), common release of information, uniform IFSP form, brochure, written public relations items, parent handbook, and parent satisfaction survey are available from LICC contact or BEST Project

2-75

JEFFERSON COUNTY, ALL OF ATCHINSON COUNTY, (EXCEPT CITY OF ATCHINSON), AND A CORNER OF DOUGLAS COUNTY

Early Childhood Coordinating Council
of Atchinson & Jefferson Counties
Contact: Ellen Millard
Northeast Kansas Educational
Service Center
601 Woodson
LeCompton, KS 66050
(913) 887-6711
FAX (913)863-2919

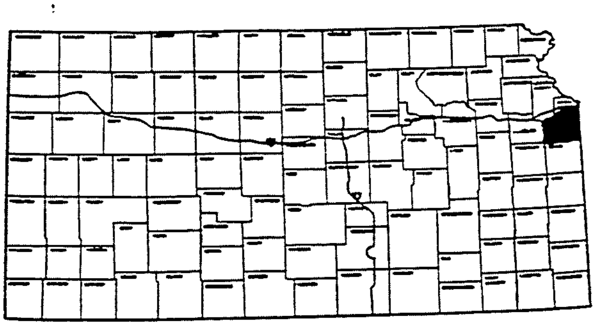


TARGET POPULATION	All children 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	LICC and Local Planning Council are the same entity; LICC shares membership with HB3113 Regional Planning Council, Special Education Transition Council, LICCs in nearby areas, local committee of Regional Drug and Alcohol Prevention Council, Jefferson County Health Coalition
YEAR ESTABLISHED	1990
FUNDING OF COUNCIL ACTIVITIES	Part H mini-grants; agencies share costs; KCCTO training
MEETING SCHEDULE	Bi-monthly: 1st Thursday of every other month, sometimes mornings, sometimes afternoons
PURPOSE	To coordinate existing services for children 0-5 and their families; to identify gaps in existing services; and to develop services to fill those gaps
CURRENT GOALS	To sponsor Week of the Young Child; host a child and family community fair; KCCTO training; arrange charitable dental care. Now pursuing 501-C3 in order to receive charitable donations; also developing by-laws
ACCOMPLISHMENTS	Providing child care training; resource guide; Identifying and bringing into the council resources that we weren't using (LICC will share information)
WRITTEN PRODUCTS	Local resource directory, common intake or referral form, common release of information form, uniform IFSP or IEP forms, brochure, surveys, and other information tools are available from LICC contact or BEST Project

2-76

JOHNSON COUNTY

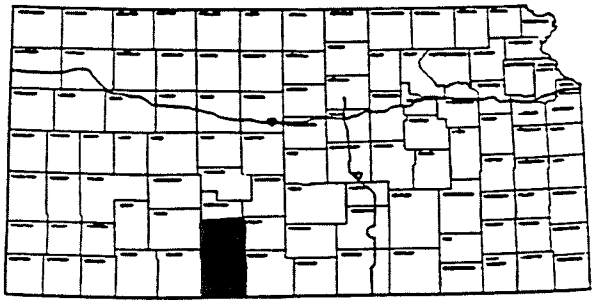
Infant Toddler Services of Johnson County Interagency Coordinating Council
Contact: Kay Richter/Ellen Condron or
Denise Godinez, Council Chair
(913) 648-2317
10201 Horton
Shawnee Mission, KS 66207
(913) 967-7676
FAX (913) 967-7679



TARGET POPULATION	Children with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Share a representative with Local Planning Council, HB 3113 Regional Planning Council, Special Education Transition Council, LICCs in nearby areas
YEAR ESTABLISHED	1993 formal council and board from grass roots effort begun in 1991
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Board and Executive Board alternate meetings each month: 1st Tuesday, 2:00 p.m., full council meets two times a year
PURPOSE	"Through a working partnership between families and the community infant toddler services, fosters and coordinates the delivery of timely, comprehensive, quality services for children age birth through 36 months, who have developmental delays or disabilities"
CURRENT GOALS	To establish contracts with all service providers; identify new provider resources; seek out new sources of funding
ACCOMPLISHMENTS	Formalized Council and by-laws; increased public awareness; established a data base (LICC will share information)
WRITTEN PRODUCTS	Local resource directory, common intake or referral form, common release of information form, uniform IFSP or IEP forms, brochure, written public relations items, and information tools are available from LICC contact or BEST Project

KIOWA AND COMANCHE COUNTIES

KiCom Interagency Coordinating
Council
Contact: Mitzi Hesser
Kiowa County Health Department
211 East Florida
Greensburg, KS 67054
316-723-2136
FAX (316) 723-3302

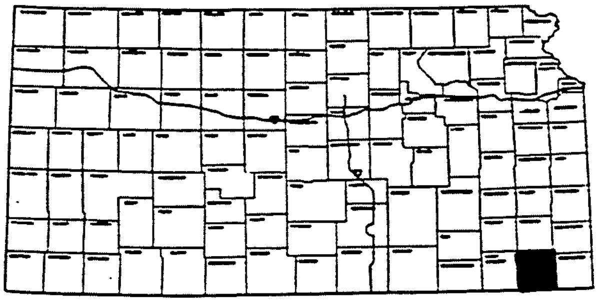


TARGET POPULATION	All children 0-21 years and their families
AFFILIATIONS WITH OTHER COUNCILS	None
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL ACTIVITIES	Part H Mini-Grants; local contributions; agencies share costs
MEETING SCHEDULE	Monthly: no regular day, noon
PURPOSE	To eliminate duplication of services
CURRENT GOALS	To improve screening clinics, (increase attendance, exposure, awareness); develop written transition Part H/Part B plan
ACCOMPLISHMENTS	Getting organized; networking; one screening clinic (LICC will share information)
WRITTEN PRODUCTS	Uniform IFSP or IEP forms, and written procedures for referral and/or transition are available from LICC contact or BEST Project

2-75

LABETTE COUNTY

Labette County Interagency
Coordinating Council
Contact: David Lindeman
2601 Gabriel
Parsons, KS 67357
(316) 421-6550 Ext 1859
FAX (316) 421-6550 Ext 1702

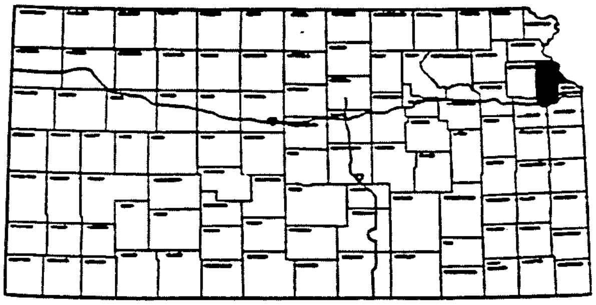


TARGET POPULATION	Children with disabilities 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	County Coalition
YEAR ESTABLISHED	1991
FUNDING OF COUNCIL ACTIVITIES	Part H mini grants; agencies share costs
MEETING SCHEDULE	Quarterly: 2nd Thursday, 8:30 - 10:00 a.m.
PURPOSE	Agencies dedicated to improving services to children and their families
CURRENT GOALS	To provide Parent Universities; distribute Family Resource Directory
ACCOMPLISHMENTS	Parent University; joint agency screening activities; Child Find Clinics; family donation for Families together Enrichment Weekend
WRITTEN PRODUCTS	Local resource directory; common release of information form

2-79

LEAVENWORTH COUNTY

Leavenworth Interagency Networking
Council (Linc-Up)
Contact: Beth Feiring
St. John Hospital
3500 S. 4th Street Trafficway
Leavenworth, KS 66048
(913) 682-3721
FAX (913) 682-1542

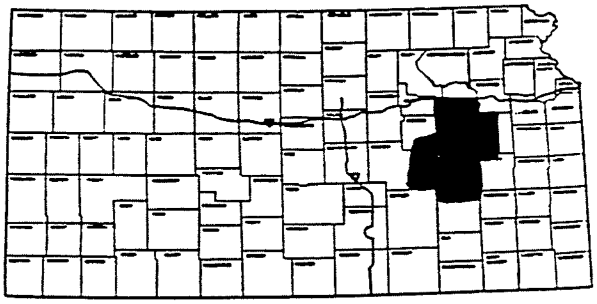


TARGET POPULATION	Children at-risk or with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares members with Leavenworth Association of NAEYC. Has an appointed representative on the LICC Special Education Transition Council
YEAR ESTABLISHED	1989
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs; St. John's Hospital
MEETING SCHEDULE	Monthly: 3rd Monday; 9:00 a.m.
PURPOSE	To provide therapy services for children with disabilites and resources for their families; to alleviate barriers in the community that affect children and families receiving services
CURRENT GOALS	To increase identification of children; to implement the forms that have been developed; to provide training to child care providers; to improve transitions from Part H to Part B
ACCOMPLISHMENTS	Bringing providers together; developing forms; establishing referral procedures; fostering a greater understanding of the law
WRITTEN PRODUCTS	Common intake or referral form, common release of information form, uniform IFSP forms, brochure, written procedures for referral and/or transitions, information tools, and consent for third party billing are available from LICC contact or BEST Project

2-80

LYON COUNTY AND PARTS OF CHASE, GREENWOOD, MORRIS, OSAGE, AND WABAUNSEE

Flint Hills Area Umbrella
Council
Contact: Judy Ball
Flint Hills Special Education
Cooperative
P.O. Box 459
216 W. 6th
Emporia, KS 66801
(316) 341-2325
FAX (316) 341-2205

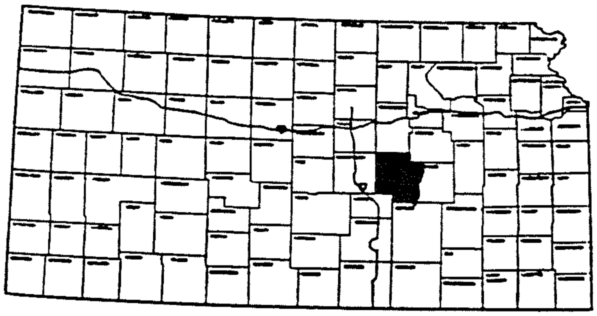


TARGET POPULATION	All children 0-21 and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares members with HB 3113 Regional Planning Council, Special Education Transition Council, Parent Connection Council. LICC and Local Planning Council are same entity
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL	Part H funds; agencies share costs
MEETING SCHEDULE	Monthly: Last Friday, 10:00 a.m. - noon
PURPOSE	To provide a way for agencies to work together to do awareness and education; to meet needs of children and families in the community; to provide a full range of services
CURRENT GOALS	To get "umbrella group" started
ACCOMPLISHMENTS	Common release form
WRITTEN PRODUCTS	Local resource directory, common release of information form, brochure, parent guide, confidentiality statement, information sheet for parent use, and mission statement are available from LICC contact or BEST Project

2-81

MARION COUNTY

Marion County Interagency
Coordinating Council
Contact: Debbi Darrow
Marion County Early
Intervention Services
601 East Main
Marion, KS 66861
(316) 382-2154
FAX (316) 382-2118

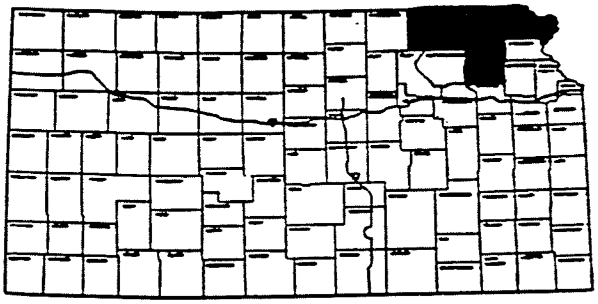


TARGET POPULATION	All people, birth to death
AFFILIATIONS WITH OTHER COUNCILS	Appointed representative of Local Planning Council, HB 3113 Regional Planning Council, Special Education Transition Council, CASSP Council, Local Committee of Regional Drug and Alcohol Prevention Council. Shares members with other LICCs in neighboring counties
YEAR ESTABLISHED	1986
FUNDING OF COUNCIL ACTIVITIES	Part H minigrant; agencies share costs
MEETING SCHEDULE	Bi-monthly: 2nd Friday of odd-numbered months, 12:00 noon
PURPOSE	To provide coordinated prevention, education, and services to support families
CURRENT GOALS	To increase parent participation
ACCOMPLISHMENTS	Improved service coordination; putting Part H program into place; monthly rotating screening throughout county for ages 0-5
WRITTEN PRODUCTS	Uniform IFSP or IEP forms, brochure, and surveys or other informational tools are available from LICC contact or BEST Project

2-82

MARSHALL, NEMAHA, BROWN, DONIPHAN & JACKSON COUNTIES

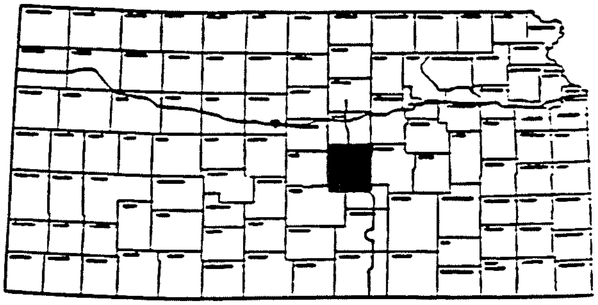
Local Interagency Coordinating Council
Contact: Suelette Bell
508 Delaware
Hiawatha, KS 66434
FAX (913) 742-4237



TARGET POPULATION	Children with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Appointed representative of HB 3113 Regional Planning Council, Special Education Transition Council
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL ACTIVITIES	Part H funds
MEETING SCHEDULE	Quarterly: 2nd Monday, 3:00 p.m.
PURPOSE	To collaborate on the provision of services for children and their families; determine what services are needed and lacking; increase efficiency; advocate for young children and their families
CURRENT GOALS	To find other funding sources; receive IFSP training; provide an IFSP coordinator in every county; redo the IFSP
ACCOMPLISHMENTS	Incorporated executive boards; increased number of children and areas served
WRITTEN PRODUCTS	Local resource directory, common release of information form, uniform IFSP forms, brochure, and directory of LICC members are available from LICC contact or BEST Project

McPHERSON COUNTY

McPherson County Council
Council on Children & Families
Contact: Virginia Walker
MCKIDS
1106 Hospital Drive
McPherson, Ks 67460
(316) 241-9590
FAX (316) 241-9410

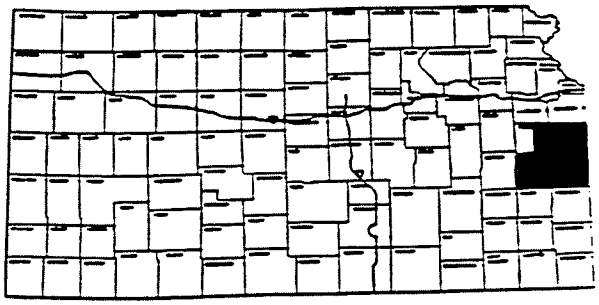


TARGET POPULATION	All children 0-21 years and their families
AFFILIATIONS WITH OTHER COUNCILS	LICC is the same as Local Planning Council and HB 3113 Regional Planning Council. Subgroups of the LICC include local committee of Regional Drug and Alcohol Prevention Center, and MCKIDS Advisory Committee. LICC has an appointed representative on a Special Education Transition Council
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Monthly; 2nd Monday, 12:00 noon
PURPOSE	To take a leadership role in the development and coordination of comprehensive systems to provide services to children and families
CURRENT GOALS	To improve support for parents; start single-parent support group; develop a community-based program for juvenile offenders; encourage social networks for parents of children with special needs
ACCOMPLISHMENTS	Initiated Head Start and Parents as Teachers; wrote a grant for youth at risk; strategic planning
WRITTEN PRODUCTS	Local resource directory (in process), interagency agreement, common intake or referral form, brochure, written procedures for transition are available from LICC contact or BEST project

2-84

MIAMI, LINN, ANDERSON, AND FRANKLIN COUNTIES

East Central Kansas Interagency
Coordinating Council
Contact: Bill Vivers
East Central Kansas
Special Education Cooperative
Box 268
Paola, KS 66071
(913) 294-2303
FAX (913) 294-5961

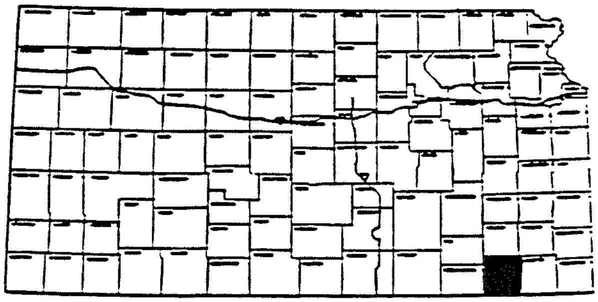


TARGET POPULATION	Children with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Appointed representative of HB 3113 Regional Planning Council and Special Education Transition Council
YEAR ESTABLISHED	1993
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Quarterly: Wednesdays, 1:30 p.m.
PURPOSE	To serve families and children
CURRENT GOALS	To get organized and establish a network of agencies which provide services
ACCOMPLISHMENTS	Getting agencies who provide services and parents together; serving children and families
WRITTEN PRODUCTS	Common intake or referral form, common release of information form, uniform IFSP form, brochure, flyer for "Count Your Kid In" (yearly screening for 0-5) are available from LICC contact or BEST Project

2-85

MONTGOMERY COUNTY

Montgomery County Interagency
Coordinating Council
Contact: David Lindeman
2601 Gabriel
Parsons, KS 67357
(316) 421-6550 Ext 1859
FAX (316) 421-6650 Ext 1702

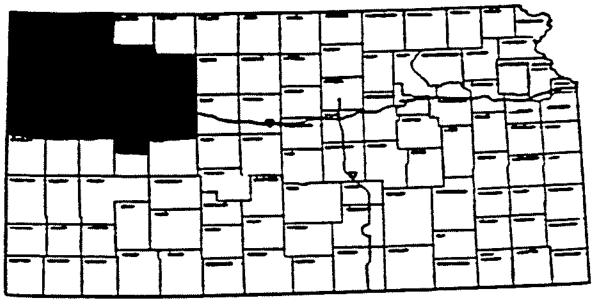


TARGET POPULATION	Children with disabilities 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	None
YEAR ESTABLISHED	1993
FUNDING OF COUNCIL ACTIVITIES	Part H mini grants
MEETING SCHEDULE	Subcommittee meets only for special projects; no regular day or time
PURPOSE	Agencies dedicated to improving services for children and families
CURRENT GOALS	To provide monthly Child Find clinic
ACCOMPLISHMENTS	Monthly Montgomery County Child Find Clinics; donation to Families Together Enrichment Weekend
WRITTEN PRODUCTS	Common release of information form

2-86

NORTHWEST KANSAS COUNTIES
(CHEYENNE, RAWLINS, SHERMAN, THOMAS, SHERIDAN, WALLACE, LOGAN, GOVE, GRAHAM, TREGO, PART OF LANE, AND PART OF DECATUR COUNTIES)

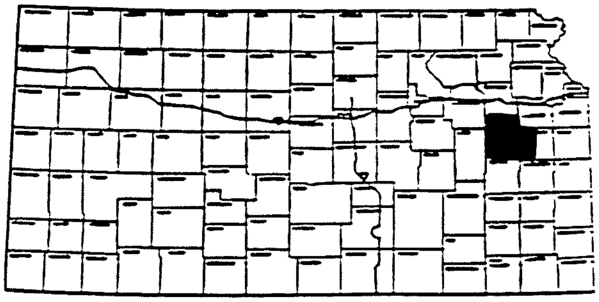
Early Childhood Coordinating Council
Northwest Kansas Educational Service Center
Contact: Kim Shafer
703 West Second Street
Oakley, KS 67748
(913) 672-3125
FAX (913) 672-3175



TARGET POPULATION	All children 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with BRITE Start Advisory Council, HB 3113 Regional Planning Councils, local committee of Regional Drug and Alcohol Prevention Council
YEAR ESTABLISHED	1989 from previous group formed in 1979 (began as the Preschool Planning Team)
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Bi-monthly: Tuesday (usually 3rd or 4th), 4:00 - 6:00 p.m.
PURPOSE	To share information with one another; to provide assistance in which to communicate and collaborate resources for children Birth-5, their families and agencies to reach the maximum potential through a cooperative local effort.
CURRENT GOALS	To share information; to develop an interagency release of information form
ACCOMPLISHMENTS	Informal networking
WRITTEN PRODUCTS	Local area resource directory is available from LICC contact or BEST Project

OSAGE AND PART OF FRANKLIN COUNTY

Osage County Blueprint Council
Contact: Valerie McNay/ Sue Thompson
Three Lakes Education Cooperative
1318 Topeka Ave.
Lyndon, KS 66451
(913) 828-3113
FAX (913) 828-3671



TARGET POPULATION	Serves all families
AFFILIATIONS WITH OTHER COUNCILS	None
YEAR ESTABLISHED	1993
FUNDING OF COUNCIL	Part H funds
MEETING SCHEDULE	Bi-monthly: 4th Thursday, noon
PURPOSE	To streamline services, coordinate among ourselves, and disseminate information
CURRENT GOALS	To produce a newsletter; develop and maintain relationships
ACCOMPLISHMENTS	Mission statement
WRITTEN PRODUCTS	Mission statement available from BEST Project

2-85

OTHER COUNTIES

There are no known LICCs in Clark, Meade, Hodgeman, and Ness Counties. They receive Infant/Toddler services from Arrowhead West (see Ford County)

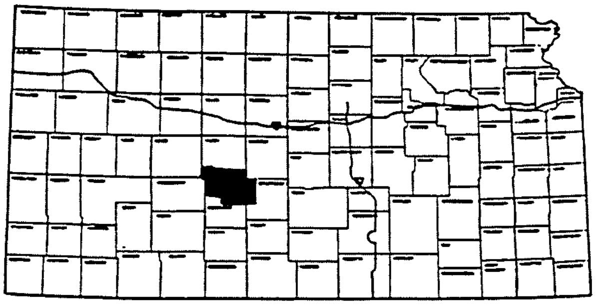
Sunflower Diversified Services (see Barton County) provides Infant-Toddler services to Rice and Stafford Counties. At present any local interagency efforts in those counties do not include a birth-through-two emphasis.

There are no known LICCs in Clay and Washington Counties. Both are served by a Resource Council but have birth-through-2 services coordinated by KDHE.

2-89

PAWNEE COUNTY

Cradles and Crayons Interagency Coordinating Council
Contact: Jane Meschberger
Sunflower Diversified Services, Inc
Sunflower Early Education Center
1312 Patton Road
Great Bend, KS 67530
(316) 792-4087
FAX (316) 792-4709

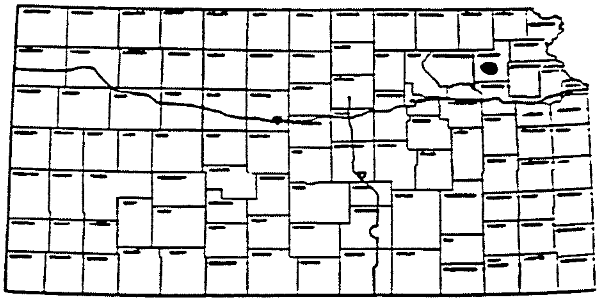


TARGET POPULATION	Children at-risk or with disabilities 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with LICCs in nearby areas
YEAR ESTABLISHED	1993
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Monthly: Fridays, evening or lunch
PURPOSE	To identify children with special needs, make services available, and inform parents
CURRENT GOALS	To improve community screening
ACCOMPLISHMENTS	Community screenings
WRITTEN PRODUCTS	Common release of information form is available from LICC contact or BEST Project

2-90

POTAWATOMI RESERVATION

Prairie Band of Potawatomi
Interagency Coordinating Council
Contact: Jackie Mitchell
15392 K Road
Mayetta, KS 66509
(913) 966-2527
FAX (913) 966-2144

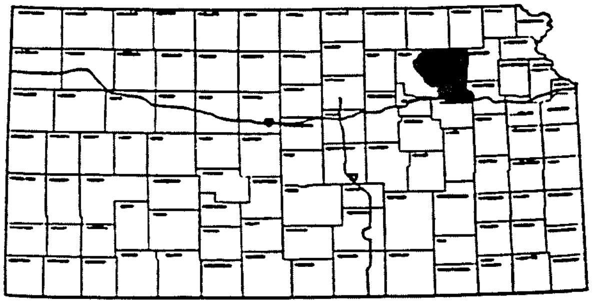


TARGET POPULATION	All children 0-5 years and their families from the Potawatomi Reservation
AFFILIATIONS WITH OTHER COUNCILS	Shares members with LICC in nearby areas and Child Protection Team
YEAR ESTABLISHED	1993
FUNDING OF COUNCIL ACTIVITIES	Part H funds; Child care and Development Block Grant; Prairie Band of Potawatomi
MEETING SCHEDULE	Quarterly: Last Monday; 1:00 pm
PURPOSE	To have all children from the Potawatomi Reservation enter the school system ready and willing to learn and succeed
CURRENT GOALS	To complete video on early childhood services
ACCOMPLISHMENTS	Sponsored a successful parent workshop; established and licensed a child care center; established a good working relationship with Head Start in same building; two members of LICC attended a Fetal Alcohol Syndrome conference in South Dakota
WRITTEN PRODUCTS	Local resource directory, uniform IFSP or IEP forms, brochure

2-91

POTTAWATOMIE AND WABAUNSEE COUNTIES

Pottawatomie/Wabaunsee Infant/Toddler
Interagency Coordinating Council
Contact: Beverly Stauffer
Pottawatomie County Health Department
320 Main Street, P.O. Box H
Westmoreland, KS 66549
(913) 457-3396
FAX (913) 457-2144

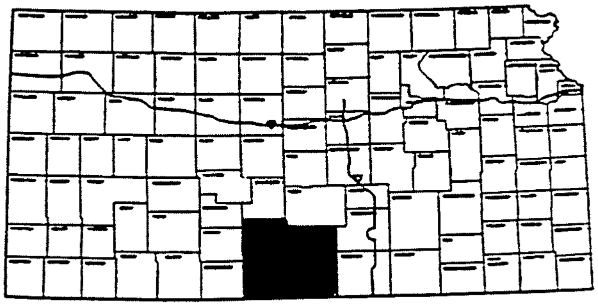


TARGET POPULATION	Children at-risk or with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	None at present
YEAR ESTABLISHED	1993
FUNDING OF COUNCIL	Part H funds; agencies share costs; schools
MEETING SCHEDULE	Bi-monthly: Tuesday, 1:00 p.m.
PURPOSE	To provide early intervention services to infants and toddlers
CURRENT GOALS	To locate and identify those children ages birth through 2 who qualify for the services provided by our council; identify and locate all appropriate agencies who have resources which meet the needs of children birth through 2; develop a comprehensive service delivery and support system for all children and families in our catchment area with special emphasis on young children who have special needs and their families; and to promote coordination of services to them through development of a network of service providers, parents, and others in the community.
ACCOMPLISHMENTS	Identifying children and providing services
WRITTEN PRODUCTS	None

2-92

PRATT, HARPER, BARBER, AND KINGMAN COUNTIES

Interagency Coordinating Council
Contact: Peggy Stucky
South Central Special Education
Cooperative
Box 177
Iuka, KS 67066
(316)-546-2227

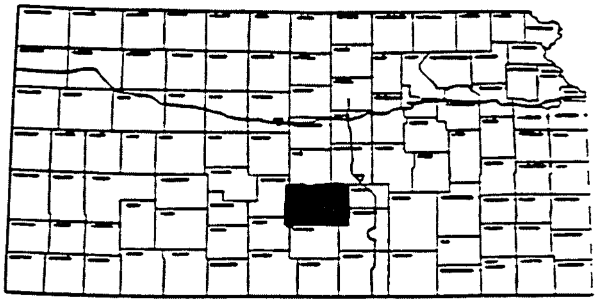


TARGET POPULATION	All children 0-21 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with Local Planning Council
YEAR ESTABLISHED	1991
FUNDING OF COUNCIL ACTIVITIES	Part H funds; local contributions; agencies share costs
MEETING SCHEDULE	Monthly: 1st Tuesday, 10:00 a.m.
PURPOSE	To provide screening clinics; to eliminate duplication of services
CURRENT GOALS	To expand membership and increase participation by more groups and agencies, including businesses and parents, and begin to focus on other children's issues
ACCOMPLISHMENTS	Resource directory; networking among agencies; increased number of screening clinics; assisting in implementing Kansas Blueprint (LICC will share information on these topics)
WRITTEN PRODUCTS	Local resource directory in progress; common intake or referral form, and uniform IFSP/IEP forms, and written procedures for referral and/or transition are available from LICC contact or BEST Project

2-93

RENO COUNTY

Reno County Planning Council
for Children and Families
Contact: Lee (Paco) Price
Early Education Center of TECH
303 East Bigger
P.O. Box 399
Hutchinson, KS 67504-0399
(316) 663-2671
FAX (316) 663-0399

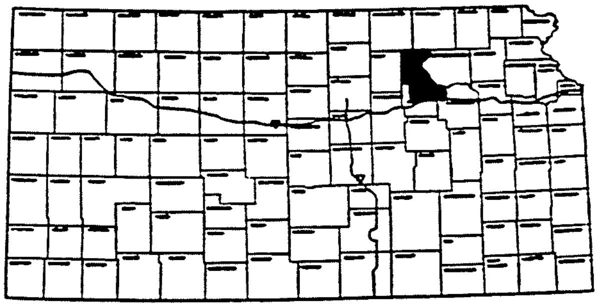


TARGET POPULATION	All children 0-21 and their families
AFFILIATIONS WITH OTHER COUNCILS	LICC shares members with HB 3113 Regional Planning Council and Head Start Policy Council. LICC is a subgroup of Local Planning Council
YEAR ESTABLISHED	1991
FUNDING OF COUNCIL	Part H funds; agencies share costs; members contribute money; grant (Homeless Taskforce)
MEETING SCHEDULE	Twice a Month: 1st and 3rd Tuesdays, 5:30 p.m.
PURPOSE	To increase the number of healthy families in Reno County by facilitating the collaboration of services; nurture a community committed to meeting the changing needs of families
CURRENT GOALS	To put an information referral network on computer
ACCOMPLISHMENTS	Submitted a Head Start grant; sponsored a Parenting Fair and Roundtable discussions; productive collaboration with other groups
WRITTEN PRODUCTS	Mission Statement, Surveys, and life cycle of a task force are available from LICC contact or BEST Project

2-94

RILEY COUNTY

Flint Hills Interagency
Coordinating Council
Contact: Candy Mitchell
or Laura Clark
P.O. Box 471
Manhattan, KS 66502
(913) 776-6363; (913) 587-2000

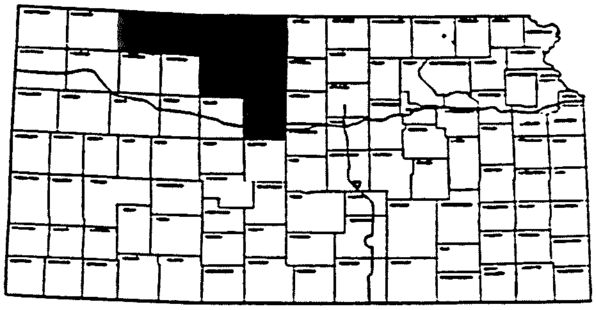


TARGET POPULATION	Children with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with LICCs in nearby areas. Appointed representative on the LICC from HB 3113 Regional Planning Council, Special Education Transition Council, Special Education Advisory Council
YEAR ESTABLISHED	1989
FUNDING OF COUNCIL ACTIVITIES	Part H funds; Kansas State Board of Education categorical aid; Medicaid monies; Chapter 1 funds, Kansas State Board of Education transportation monies; Federal funds
MEETING SCHEDULE	Monthly: Last Tuesday of Month, noon or 7 p.m.
PURPOSE	To serve children ages 0-3 with disabilities and their families
CURRENT GOALS	To improve transition into services; ease transition at age 3; improve services for children with autism; maintain level of services
ACCOMPLISHMENTS	Providing full year round services at no cost
WRITTEN PRODUCTS	Local resource directory, common intake or referral form, common release of information, uniform IFSP forms, brochure, written procedures for referral and/or transition, surveys, radio spots, and TV video are available from LICC contact or BEST Project

2-95

ROOKS, SMITH, NORTON, PHILLIPS, OSBORNE, RUSSELL, AND DECATUR COUNTIES

North Country Connection
Interagency Coordinating Council
Contact: Vicki Runge
Kid-Link/DSNWK
1327 Main, Suite 2
Stockton, KS 67669
(913) 625-5678
Fax (913) 625-8204

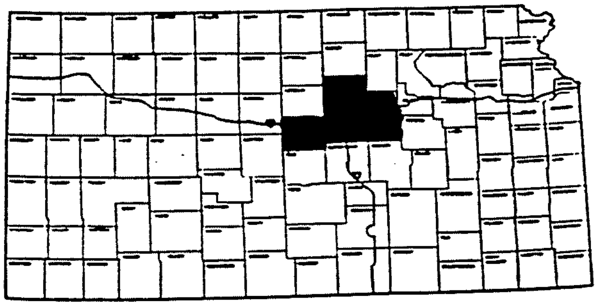


TARGET POPULATION	All children 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	LICC has an appointed representative on Special Education Transition Council and LICC in nearby areas. LICC shares members with HB 3113 Regional Planning Council and local committee of Regional Drug and Alcohol Prevention Council
YEAR ESTABLISHED	1991
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Quarterly: 3rd Thursday, 10:00 a.m.
PURPOSE	To network among key people in the community
CURRENT GOALS	To produce a resource directory; to increase awareness of on-going screening
ACCOMPLISHMENTS	Establishing the membership list and getting the people to commit to attending
WRITTEN PRODUCTS	Local resource directory, common intake or referral form, common release of information form, uniform IFSP or IEP forms, and brochure are available from LICC contact or BEST Project

2-96

SALINE, OTTAWA, ELLSWORTH, AND DICKINSON COUNTIES

Salina Area Interagency
Coordinating Council
Contact: Joyce Trower
St. John's Regional Health Center
Infant Stimulation-Child Development
139 N. Penn
Salina, KS 67401
(913) 823-4382
Fax (913) 823-4357

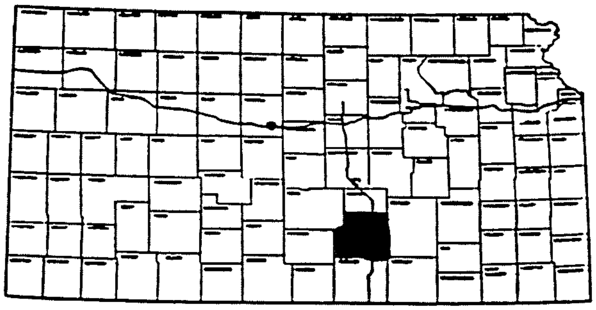


TARGET POPULATION	Children 0-5 years at-risk or with disabilities and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with HB 3113 Regional Planning Council
YEAR ESTABLISHED	1985 from previous group formed in 1979
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Monthly: 3rd Tuesday, 4:15 p.m.
PURPOSE	To provide services to children and families from birth through age 5, improve screening, evaluation, intervention, and parental support
CURRENT GOALS	To establish a parent support group; revise transition plan for age 3
ACCOMPLISHMENTS	Format for transition; public relations video; community education through noon lecture program connected with clinics (LICC will share information on these topics)
WRITTEN PRODUCTS	Local resource directory, common release of information, brochure, video, parent guide, screen form, and referral for evaluation are available from LICC contact or BEST Project

2-97

SEDGWICK COUNTY

Sedgwick County Early Childhood
Interagency Coordinating Council
Contact: Lorraine Bockorny
Rainbows United, Inc.
2615 Wellesley
Wichita, Ks 67220-2496
(316) 684-7060
FAX (316) 684-5534

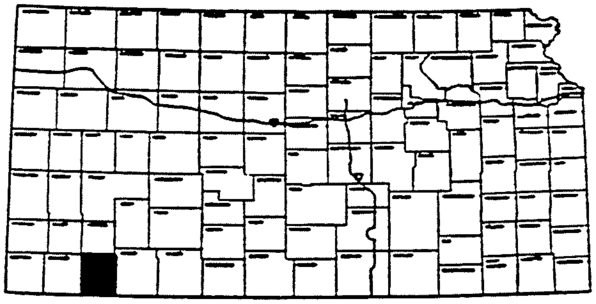


TARGET POPULATION	Children with disabilities 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares members with: Local Planning Council (HB 3113 Regional Planning council), local Mental Health Prevention Council, Project Freedom, Drug Affected Baby Task Force, Child Watch, Special Education Transition Council, County Alliance of Rehabilitation Efforts, LEA Special Education Advisory Council.
YEAR ESTABLISHED	1985, initially formed in 1979
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs, county mill levy
MEETING SCHEDULE	Steering Committee - Monthly: 3rd Thursday, 8:30 a.m. Full Council meets Quarterly: 3rd Thursday, 10:00 a.m.
PURPOSE	To insure that a comprehensive system of integrated services is available for 0-5 in the Sedgwick County area to all children with, or at risk for, developmental disabilities and their families
CURRENT GOALS	To accomplish strategic planning for public awareness, screening, family focus, funding and central point of entry
ACCOMPLISHMENTS	Developed a "Bill of Rights" for children; developed the interagency screening clinic; Connecting Point project for single point of contact
WRITTEN PRODUCTS	Brochure, survey or other information tools, guidelines for operation of the Steering Committee and Council, job description for coordinator, forms for monthly screenings, inservice training packet on Part H and LICC, and agreement between Rainbows United and LICC are available from LICC contact or BEST Project

2-98

SEWARD COUNTY

Parents and Children Together, Inc.
(PACT, Inc.)
Interagency Coordinating Council
Contact: Jan Nondorf
624 Grant
Liberal, KS 67901
(316) 626-3824
FAX (316) 626-3830

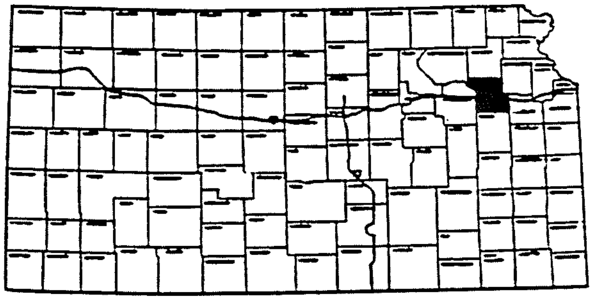


TARGET POPULATION	Children at-risk or with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares members with HB 3113 Regional Planning Council, Special Education Transition Council, and local committee of Regional Drug and Alcohol Prevention Council
YEAR ESTABLISHED	1992
FUNDING OF COUNCIL ACTIVITIES	Part H funds; county mill levy; local contributions; school district; Chapter I
MEETING SCHEDULE	Bi-monthly: 2nd Thursday, noon
PURPOSE	To provide services to families and children 0-3 eligible for services
CURRENT GOALS	To remain financially stable and continue to find additional sources of income; to provide packets for mothers of newborns
ACCOMPLISHMENTS	Increase in referral sources; improved public awareness
WRITTEN PRODUCTS	Common intake or referral form, common release of information form, uniform IFSP forms, brochure (also in Spanish), and a packet of information for new mothers are available from LICC contact or BEST Project

2-99

SHAWNEE COUNTY

Topeka-Shawnee County Local
Interagency Coordinating Council
Contact: Bonnie Gonzales
1615 West 8th Street
Topeka, KS 66606
(913) 233-8961

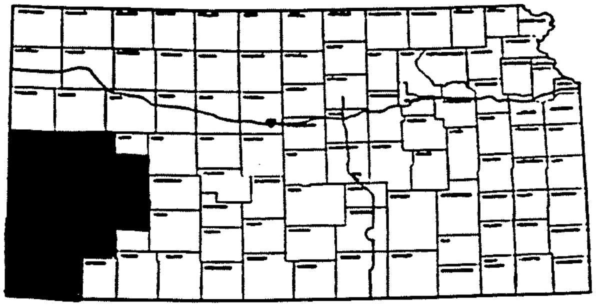


TARGET POPULATION	Children with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with Special Education Transition Council, LICCs in nearby areas, Local committee of Regional Drug and Alcohol Prevention Council. Appointed representative on the LICC from Local Planning Council, HB 3113 Regional Planning Council, Preschool Interagency Task Force
YEAR ESTABLISHED	1991 from previous informal group formed in 1986
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs; donated services
MEETING SCHEDULE	Monthly: 4th Wednesday, 1:00 p.m.
PURPOSE	To support families, assuring that their child with special needs will receive timely and comprehensive services
CURRENT GOALS	To readdress transition issues; parent brochure and handbook
ACCOMPLISHMENTS	Developed a Topeka Tots Team to bridge gaps in service
WRITTEN PRODUCTS	Local resource directory, service matrix, common release of information, common intake or referral form, uniform IFSP or IEP forms, brochure, and written procedures for referral and/or transition products are available from LICC contact or BEST Project

2-100

SOUTHWEST KANSAS COUNTIES
(FINNEY. KEARNY, HAMILTON, STANTON, GRANT, HASKELL, MORTON, STEVENS, GREELEY, WICHITA, SCOTT, AND PART OF LANE AND GRAY COUNTIES

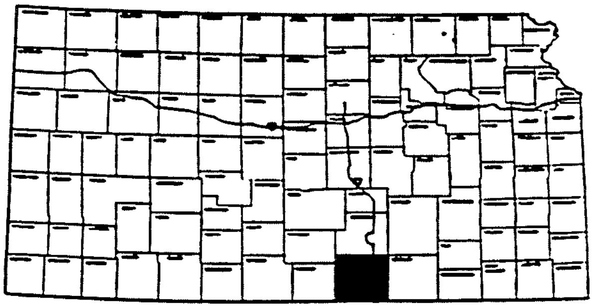
Southwest Regional Health and
Social Services Council
Contact: Nancie Linville
714 Ballinger
Garden City, KS 67846
(316) 275-0291
FAX (316) 275-0333 (call first)



TARGET POPULATION	All children 0-21 years and their families
AFFILIATIONS WITH OTHER COUNCILS Regional	LICC is subgroup of Local Planning Council, Community Service Council, Shares membership with HB 3113 Planning Council, Special Education Transition Council, LICCs in nearby areas, local committee of Regional Drug and Alcohol Prevention Council
YEAR ESTABLISHED	1989, pre-existing group since 1970's
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs
MEETING SCHEDULE	Monthly: 1st Tuesday, 11:30 - 1:00 p.m.
PURPOSE	To work together to increase services for children birth - 21 and their families
CURRENT GOALS	To complete the community needs assessment; discuss how to work as an ICC with a larger project; reflect diversity of community in participation on Council
ACCOMPLISHMENTS	Accomplished community needs assessment; brought focus of Corporation for Change to our community; began the Community Vision Now program (LICC will share information)
WRITTEN PRODUCTS	Common release of information form, video, information notebook for ICC members (activities, minutes, goals, mission statement) are available from LICC contact or BEST Project

SUMNER COUNTY

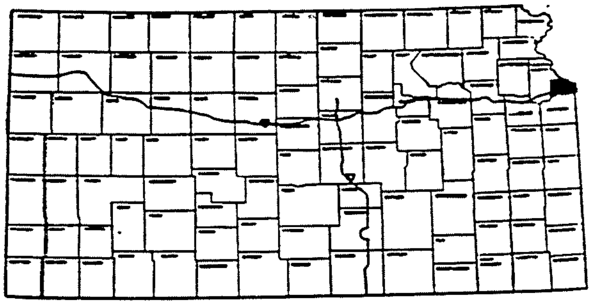
Sumner County Interagency
Coordinating Council
Contact: Doug Greer
Futures Unlimited, Inc.
2410 North A
PO Box 130
Wellington, KS 67152
(316) 326-8906
FAX (316) 3236-7796



TARGET POPULATION	All children 0-5 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares members with Local Planning Council, Special Education Transition Council, CASA
YEAR ESTABLISHED	1991, from previous group formed in 1989
FUNDING OF COUNCIL ACTIVITIES	Part H funds; Futures Unlimited
MEETING SCHEDULE	Quarterly: Fridays, noon
PURPOSE	To serve as applicant for Part H funding, sharing information, and find ways to work together as agencies
CURRENT GOALS	To work on county wide screening; form a core group of members
ACCOMPLISHMENTS	Resource manual; accessing of KDHE funds; election of a community person as vice-chair
WRITTEN PRODUCTS	Local resource directory available from LICC contact or BEST Project

2-102

WYANDOTTE COUNTY



Wyandotte County Local
Interagency Coordinating Council
Infant\Toddler Service System
Contact: Ginger Gearheart
1333 South 27th Street, Suite 300
Kansas City, KS 66106
(913) 722-1115 or 551-3700
FAX (913) 551-3706

TARGET POPULATION	Children at-risk or with disabilities 0-3 years and their families
AFFILIATIONS WITH OTHER COUNCILS	Shares membership with LICCs in nearby areas, Child Abuse Prevention Council, and Special Education Transition Council. LICC is a subgroup of Local Planning Council. LICC has an appointed representative on HB 3113 Regional Planning Council, and Local Committee of Drug and Alcohol Prevention Council
YEAR ESTABLISHED	1993
FUNDING OF COUNCIL ACTIVITIES	Part H funds; agencies share costs; SRS Block Grant; County mill levy; Kansas State Board of Education categorical aid
MEETING SCHEDULE	Quarterly: Wednesdays, afternoon
PURPOSE	To build a community-wide network of comprehensive service delivery by a creation of a set of policies and practices: 1. that assure easy access to services, 2. that increase availability of services, and 3. that enhance quality of services
CURRENT GOALS	To improve interagency communication and develop a positive "climate" for working together in our local system; To improve parent and public relations for Wyandotte County; To provide ongoing staff development to parents and professionals in training that fits their needs; and To form interagency partnerships to knit a seamless web of services in order to provide high quality comprehensive service delivery
ACCOMPLISHMENTS	Team-building retreat; signing of interagency agreements; created toy lending library; developed transition planning NICU to community; developed small play groups; and developed 3 year action plan
WRITTEN PRODUCTS	Local resource directory, service matrix, common referral form, common release of information, uniform IFSP forms, brochure, written procedures for referral and/or transition, surveys, presentation package, display board, physicians packet, special referral form for NICU to home are available from LICC contact or BEST Project

2-103

RESOURCES

Cripe, J.W., & Mayhall, C. (n.d.) Developing local planning councils: Getting started. Parsons, KS: University of Kansas Affiliated Program.

Cripe, J.W., & Mayhall, C. (n.d.) Developing local planning councils: Strategic planning. Parsons, KS: University of Kansas Affiliated Program.

Cripe, J.W., & Mayhall, C. (n.d.) Developing local planning councils: Care and feeding of your local council. Parsons, KS: University of Kansas Affiliated Program.

Hazel, R., Barber, P.A., Roberts, S., Behr, S.K., Helmstetter, E., & Guess, D. (1988). A community approach to an integrated service system for children with special needs. Baltimore, MD: Paul H. Brookes Publishing Company.

Kagan, S.L. (1991). United we stand: Collaboration for child care and early education services. New York: Teachers College Press.

Melaville, A.I., & Blank, M.J. (1993). Together we can: A guide for crafting a profamily system of education and human services. Washington, DC 20402-9328: U.S. Government Printing Office, Superintendent of Documents, Mail Stop SSOP.

National Association of State Boards of Education. (1991). Caring communities: Supporting young children and families. Alexandria, VA: Author.

Rosenkoetter, S.E., Hains, A.H., & Fowler, S.A. (1994). Bridging early services for children with special needs and their families: A practical guide for transition planning. Baltimore: Paul H. Brookes Publishing Company.

Sarason, S.B., & Lorentz, E. (1979). The challenge of the resource exchange network. San Francisco: Jossey-Bass, Inc.

Sarason, S.B., Carroll, C., Maton, K., Cohen, S., & Lorentz, E. (1977). Human services and resource networks: Rationale, possibilities, and public policy. San Francisco: Jossey- Bass, Inc.

Sugarman, J. 1991). Building early childhood systems: A resource handbook. Washington, DC: Child Welfare League of America, Inc.

Swan, W.W., & Morgan, J.L. (1993). Collaborating for comprehensive services for young children and their families: The local interagency coordinating council. Baltimore, MD: Paul H. Brookes Publishing Company.

DRAFT

APPENDIX

Kansas Department of Health and Environment

Proposed New Regulation

4/18/94

28-4-565. Community responsibilities. (a) Each community shall have a local interagency coordinating council (ICC) that has as one of its purposes the coordination of early intervention services for infants and toddlers with disabilities and their families.

(1) The local interagency coordinating council shall consist of members who reflect the community, including at a minimum:

(A) Two parents of children with disabilities;

(B) a representative of a health or medical agency;

(C) a representative of an educational agency; and

(D) a representative of a social service agency.

(2) The names of local interagency coordinating council members shall be submitted to and acknowledged by the state lead agency.

(3) The chair of the council shall be elected by the local interagency coordinating council; the name of the chair shall be communicated to the state lead agency.

(4) The responsibilities of the local interagency coordinating council include, but are not limited to:

(A) to identify local service providers who can provide early intervention services to infants and toddlers with disabilities and their families,

(B) to advise and assist local service providers, and

(C) to communicate, combine, cooperate, and collaborate with other local councils on issues of concern.

(b) Each community, in collaboration with its local ICC, shall develop a plan describing the system for coordinating early intervention services. The plan shall include:

(1) identification of a local lead agency, which shall be acknowledged by the secretary of the state lead agency; and

(2) identification of a local fiscal agency, which shall be acknowledged by the secretary of the state lead agency. The local lead agency and local fiscal agency may be the same agency, if the local lead agency is a legal entity.

(3) a description of the child find plan, including assurance that child find activities are available at least monthly, and a description of the child find plan;

(4) a description of identified community needs and resources;

(5) a description of written interagency agreements or memoranda of understanding, and how those agreements are used in the development of IFSPs for eligible children and families;

(6) a public awareness program that informs community members about child find activities, the central point of contact for the community, and the availability of early intervention services;

(7) an assurance that the following information is available in the community:

(A) The following services shall be at no cost to eligible infants and toddlers and their families:

(i) Child find activities;

(ii) evaluation and assessments;

(iii) family service coordination;

(iv) administrative and coordinative activities related to the development, review and evaluation of the individualized family service plan (IFSP), and implementation of procedural safeguards and other components of the statewide system of early intervention services; and

(v) early intervention services, as described in K.A.R. 28-4-562, included in the infant or toddler's IFSP or otherwise determined to be necessary as the result of a formal evaluation process.

(B) Parents shall not be required to pay deductibles, coinsurance, or amount of charges exceeding payment rates related to private health insurance or other third party payment sources for charges for early intervention services as listed previously in (A) (i) through (v).

(C) Parents shall be informed, in writing, that they are not required to approve filing of claims with their private insurance policy or policies, or to access Medicaid or other payment sources. Written consent from the parents shall be obtained prior to filing claims.

2-107

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(D) Parents without health insurance or who do not choose to permit filing claims with their health insurance shall not be required to make payment for charges for early intervention services listed previously in (A) (i) through (v).

(E) Parents shall be assured that their resources to pay for necessary early intervention services shall not result in the denial of services or determine the extent of necessary early intervention services available to the child or the child's family.

(c) Each community desiring federal and state Part H funds shall submit an annual grant application to the state lead agency. This grant application shall:

(1) include the plan for coordination of early intervention services, as described in K.A.R. 28-4-565(b); and

(2) be in compliance in accordance with the grant application materials provided by the state lead agency. (Authorized by and implementing K.S.A. 1992 Supp. 75-5649; effective P-________________.)

2-108

K•A•R•F
Kansas Association of Rehabilitation Facilities
Jayhawk Tower • 700 Jackson • Suite 212 • Topeka, Kansas 66603-3757
(913) 235-5103 • Fax (913) 235-0020

Testimony to the House Select Committee on MR/DD Issues
January 25, 1995

Presented by:

Tom Laing, Executive Director
Kansas Association of Rehabilitation Facilities

Thank you Representative Pottorff and members of the committee for inviting our organization today.

Let me begin by introducing the Kansas Association of Rehabilitation Facilities.

KARF is 43 community-based not-for-profit organizations, and two county run organizations which provide services for people with disabilities.

Most of our member organizations were founded in one of four ways... by families of children with disabilities, such as TARC of Topeka... by service organizations, such as KETCH of Wichita founded by the Kansas Elks... by individuals with a desire to address a charitable cause, such as Capper's in Topeka, which was founded by Senator Arthur Capper... or as a coordinated community effort involving families, friends and concerned neighbors.

Our membership includes all but two of the state's CMRC's, with the balance being affiliates. We have large multi county members, and small single county members and counties where members work together side by side.

As you can see there are lots of differences among our members, but of all them you can say this...

They are locally governed, locally managed, and to a substantial degree, locally financed by more than ten million dollars in voluntary property tax levies, and several hundreds of thousands of dollars of local donations.

That is the common characteristic that explains their uniqueness.

House SC on Developmental
Disabilities - 1-25-95
Attachment 3

The current system encompasses broad ranges of opinions and philosophies:

You have heard from many groups this week, and with each we share the most important principle, i.e. the respect for the rights and dignity of the people we serve.

For policy makers the span of philosophies and opinions is a challenge. Who speaks for everyone? The answer is no one can claim to do so.

But who serves everyone, within the limits of resources, and irrespective of philosophy? I believe the answer is the current system of CMRC's and their affiliates.

One of the things to note is that not all parents are in agreement with the changes taking place. I have visited with parents of children living in state institutions, in ICF's/MR in small group homes and living in independent apartments. Their opinions are vastly different.

Likewise within our own organization, some are more conservative than others. Some want bold change today, others want to see what the future holds rather than put the current system, that is doing a lot of good, at risk. Each, in addition to their duty to the state, has an original responsibility to serve the people in their community. They and their boards attempt to manage responsibly to assure that services in place are not jeopardized as a result of short-sighted planning or hasty execution.

The partnership with the state has strained the fabric of local organizations somewhat, but as yet none of our organizations has turned its back on the needs of those whom the state had previously served. The balance of partnership between local needs and state needs is tentative, but still in place.

Our work in the community.

We provide a range of services, including education and training, vocational, residential, pre-school to retirement, etc.

Each of our organizations is actively involved with families ... some have developed formal family advisory groups... in other cases, their founders and many of their board members are family members, and thus family input is a part of the ongoing evolution of their organizations.

Each of our organizations is engaged in the work of promoting independent living activities...

Some of the current Independent Living Centers were started and funded and nurtured by our members, and many independent living styled services have been and continue to be provided by members of our organization... the philosophy between organizations may be different, board composition may be different... but we are all, one way or the other, in the business of promoting independent living.

In fact, our members began the very earliest IL services for people with developmental disabilities when the IL movement did not serve the needs of people with mental retardation.

System reforms.

You have heard it said that the system must make it easier for other organizations to access state and federal dollars. In fact the system is in place to do that, under statutes adopted by the Legislature twenty years ago.

At the time, the Legislature must have contemplated the future, because the resulting laws appear to have anticipated that a variety of providers would want to access the same dollars.

They addressed the issue through the concepts of local determination, local coordination and local accountability.

Local government was assigned by the law to designate either themselves or a not-for-profit entity to coordinate service.

In all but three counties, the local designated entity is a community not-for-profit organization. These organizations, all but one of whom are KARF members, have filled the coordinating role for their region or community. The system did not limit funding to those designated as CMRC's, but included broad language to allow for other groups to become affiliates and have access to funding. That system is still in place today.

Like others who have spoken, we also want to see changes in the system, and want all concerns to be addressed. We urge this committee to take on that task. But unless someone can give you good reasons why we should, as a state, dismantle the existing community system and start from scratch, I recommend you utilize the existing system, and build on it to make it a better system for all consumers and communities.

Service gaps --

Let me touch on a few gaps, as have been identified for me by members of the organization over the past two years.

Transition --

Transition services address that time at the end of a person's high school career, when they prepare to move into the community as adults. That system is still not meeting the expectations of people in many communities. It appears that a stronger partnership is needed between the state agencies charged with the work, and that all involved need to cooperate to make the system better.

Equally important is that we re-configure our language, and recognize other transition needs... such as that time in a child's life in transition from preschool to school, and that time in the life of an older adult who needs to confront the issues of aging, and the economic needs of the retirement years.

A system-wide examination of life transitions, and the special impact on those with disabilities, is needed.

Employment --

Like women, or people of color or any group whose entry into the economic mainstream has been impaired by discrimination, employment issues are stubborn for people with disabilities.

The reluctance of employers to hire people with disabilities is slowly being overcome, and in fact, from the field I am told that among the major sectors of the society, the business community has been a more supportive player than government, or schools or the medical community.

We want to see more movement for mainstream community employment, but two hundred years of history is not easily overcome.

One stopgap still in use is the sheltered workshop model. The sheltered workshop does not fit the current paradigm shift to fully inclusive community employment, but through such settings, some job training does take place, and some modest income is realized both for the consumer and also to support the work of the community program network. The bottom line is not unique to people with disabilities. We need decent jobs with decent benefits, and discriminatory employment practices need to end.

Health Care --

It cannot be said too often that people who cannot find available, affordable health care or health insurance cannot live to their maximum independent capacity. That problem faces most of our people. It is a national disgrace that the only way out in these cases is to stay on welfare.

The key is in the private sector. Private sector health care providers from doctors to dentists need to learn more about our consumers' needs (and we have a duty to help them in that regard). And our health system educators need to do a more thorough job of raising the health issues of the disability community in our medical school and in nursing schools around the state.

The state may need to take a more active role in this issue, but this problem will not be solved by spending more money, unless medical professionals also take a lead within their professions to commit to service based on need. Free market medicine is not a friendly market to poor people, or hard to serve people, or people in isolated rural communities.

Housing --

When there was no housing available many of our members invested local, state and federal dollars in group housing. At the time, it was not only acceptable but encouraged by the state to build these facilities.

However, many communities would not allow such homes in residential neighborhoods, and so many of these houses today do not meet the need for integration. Additionally, despite the state's support at the time, the state today considers such homes to meet standards for community inclusion.

There is the obvious gap, i.e. the need for available affordable housing, but there is also this gap... What do you do with group homes constructed with the blessing of the government after the government's blessing is withdrawn due to new state policy?

At the present time, community organizations who can sell those homes do so... those who cannot are stuck in a financial swamp only partly of their making.

System Gaps --

In addition to service gaps, many of which can only be covered by a reallocation of state resources, there are system gaps... conceptual pot holes that can be filled by state policy makers such as yourself...

Communication gaps --

We continue to work to find ways to better listen and hear the articulated needs of consumers and families.

We also need to communicate more candidly with parents.

We must include in our dialogue the fact that services are limited in part by the scarcity of public resources. It is misleading and wrong to leave families with the impression that all things are possible through state and federal funding. We must always ask what are the family's resources and capacities, and what can be done to supplement, not replace, their efforts.

Another communications gap exists between and among stakeholders. Increased state and federal support for advocacy networks and service providers has not elevated the level of cooperation.

When tax dollars fund competing service networks, then a discipline should be imposed on all who accept the money that, within their region or community, they will regularly come to the table with other stakeholders to address mutual concerns.

Dream --

The dreams of the current network of community providers are lived out little by little each day, and are made manifest by the actions of the citizens we serve. But such dreams are also tempered each day by reality.

The big dream is no special programs, no special protection, no special committees or "special anything" for people with disabilities. That would mean that we had all gotten the right things done.

A more immediately do-able dream has come true in part with the creation of this committee. Everyone in this room has believed for a long time that if we could just get some front burner attention... which we now have... that everyone would get a clearer picture of what great things are in store for this state when everyone gets a chance to contribute.

K•A•R•F
Kansas Association of Rehabilitation Facilities
Jayhawk Tower • 700 Jackson • Suite 212 • Topeka, Kansas 66603-3757
(913) 235-5103 • Fax (913) 235-0020

Dear Legislator:

Throughout the session you will review a number of bills with a potential to have an impact on the lives of people with disabilities... related to their ability to secure needed services, or to enjoy employment and residential opportunities in their home communities.

We will contact you as needed on specific legislation; however, so that you may better understand the issues facing community service providers, we have compiled the attached "1995 Legislative Platform" of KARF positions. It is this "platform" by which we will measure and evaluate legislation this year.

Please review this and use it as a reference document, so you have a better feel for the opinions of the members of our organization, including those working in your district.

Thank you for your time and consideration.

Sincerely,

Tom Laing

Tom Laing, Executive Director
The Kansas Association of Rehabilitation Facilities

The public is demanding a "**new approach**" to managing public resources...

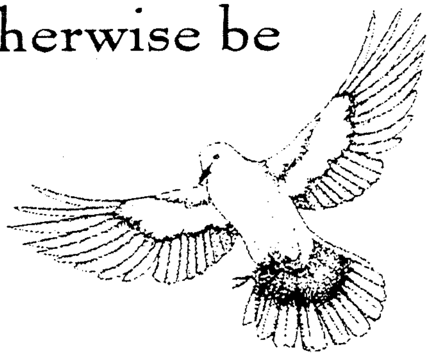
For KARF, this "**new approach**" is nothing new.

Our members have been on the cutting edge of this "**new approach**" for 25 years.

Consider this...

3-8

W PROMOTE INDEPENDENCE among people with disabilities who might otherwise be dependent on the state.



$$ We BRING TAX DOLLARS BACK TO THE COMMUNITY to finance local efforts to meet local needs.

We now serve a large number of people formerly served by state mental retardation institutions, making it possible to DOWNSIZE STATE GOVERNMENT.

We have shown that not-for-profit community services can effectively PROVIDE PUBLIC/PRIVATE PARTNERSHIPS to better serve Kansas needs.

If you want to know how to help us to continue to meet the needs of our communities and our state, please review the following information...

The Kansas Association of Rehabilitation Facilities:

1995 Legislative Agenda

The mission of the Kansas Association of Rehabilitation Facilities is to serve its members through Support, Technical Assistance and Advocacy. Through its membership, KARF provides Direction and Leadership at the local, state and national levels to support people with disabilities.

The 45 Members of KARF propose the following agenda for the 1995 Legislative Session:

I. MR/DD Reform:

KARF's principal legislative goal is to expand the current statutory framework by which services for people with disabilities are funded and administered. This initiative should reform MR/DD service delivery systems so that people with disabilities are assured the opportunities they need to make choices in life.

We support a legislative framework which addresses:

(1) Input from people with disabilities and their families; (2) High quality services; (3) Efficient use of tax dollars; (4) Complementary services vs. duplicative services; (5) Community based responsibility and accountability; (6) State monitoring vs. state management; and (7) Coordination and communication at the state and local levels.

II. To Improve the Quality of Life for Kansans with Disabilities:

A. We support effective laws and strong enforcement of laws against the abuse, exploitation and neglect of dependent persons to assure that Kansans with disabilities are protected against those who would jeopardize their lives, safety and dignity.

B. We support the expansion of community employment opportunities for people with disabilities and policies to enhance the creation of such employment opportunities, including but not limited to tax incentives for supportive employers.

III. To Assure that Kansans with Disabilities Benefit from the Efficient Delivery of State Sponsored Programs :

A. We support and encourage the exercise of government monitoring to assure outcomes-based fiscal and programmatic accountability by all recipients of MR/DD funding, including state recognition and adoption of the KARF "Panoramic Quality Assurance Statement" (see attached).

B. We support partnership planning between government and community based programs within which community providers have an acknowledged right to negotiate openly and equitably in matters relating to contracts and rates.

C. We support laws that allow communities to retain the right to designate and finance programs for persons with disabilities.

D. We support a study of SRS to examine the feasibility of a separate state agency for disability policies and programs.

IV. To Assure that Kansans with Disabilities Receive the Level of Support Needed to Meet Service Expectations as Envisioned by the Governor and the Legislature :

A. We support the expansion of the family support program.

B. We support adequate funding for locally developed community programs and for state/federal sponsored programs administered by community providers, to be financed via reallocation of existing resources to reflect the shift from institutional services to community based services.

C. We support uniformity in reporting of services provided and costs incurred by community programs.

D. We ask the legislature and the administration to review the compliance with current state-use laws (which set aside certain contracts for products/services manufactured/provided by employment training programs for people with disabilities).

E. We support state policies that maximize the receipt of available federal assistance.

F. We urge the legislature to consider exempting ADA compliance costs from the current local property tax lid law as well as continuing the current exemption of MR program and building levies.

For more information regarding KARF legislative positions, Please call our state office 913-235-5103.

KANSAS ASSOCIATION OF REHABILITATION FACILITIES

ADOPTED
JANUARY 1994

QUALITY ASSURANCE
A PANORAMIC APPROACH

One of the shared beliefs and values expressing the mission and purpose of the members of the Kansas Association of Rehabilitation Facilities is a belief in:

> **Integrating individuals with disabilities into community programs/services, business and industry, and social settings without compromising the quality of services needed to meet each person's need.**

To help adults and children with disabilities have opportunities to increase their independence and enjoy the same rights, dignity and respect as persons without disabilities, KARF supports development and implementation of a comprehensive quality assurance system that will ensure the delivery of services people want and need.

A comprehensive quality assurance system will:

1. Apply to all providers and funders of service.
2. Include measurable standards that are built upon satisfying people's needs and choices, within the resources available to them.
3. Respect each person's rights, hold them responsible for their actions, and recognize the dignity of taking risks.
4. Reflect community values as locally determined.
5. Support active ways to enhance staff morale.
6. Be reasonably attainable within available resources.
7. Measure the efficiency and effectiveness of the provider's business practices.
8 Verify whether desired service outcomes are achieved.
9. Be continuously responsive to changes in technology and service delivery.
10. Contain internal and external safeguards such as an abuse/neglect reporting system, an advocacy network incorporating individual legal representation, equal access to law enforcement protection, and mechanisms to meet and maintain basic health and safety needs.
11. Support the equality of partnership between providers and funders of service through establishing clear lines of authority and accepting input into policy development and implementation.
12. Provide support and education to non specialized services systems and staff.

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Such a system would be based upon cooperation among providers and funders, a commitment to avoiding duplication of standards and principles, and responsive to the numerous stakeholders affected by the delivery of services to persons with disabilities. Among those stakeholders are:

(1) Consumers - which includes individual children and adults whether they are awaiting service, served in state institutions, large or small bed ICF/MR, or community programs
(2) Families and significant others in the lives of individual consumers
(3) Department of Social and Rehabilitation Services
(4) Governor's Office
(5) Departments of the Executive Branch such as Health and Environment and Office of Fire Marshal
(6) Legislative Branch of State Government
(7) Federal Government - Executive and Legislative
(8) Local and County Governments
(9) Providers - which includes providers of services specific to persons with disabilities as well as providers of generic services
(10) Citizens

The KARF recommends joint efforts in developing the framework of the Quality Assurance system with an emphasis on:

1. Establishing service principles that guide service systems in organizing and providing supports to people with disabilities that use and maximize generic community resources,
2. Building and maintaining complementary, not duplicative policies and procedures,
3. Granting deemed status for achieving and maintaining national accreditation as a substitute for state licensure.
4. Developing Kansas specific standards to complement those present in accreditation systems to use while providers seek accreditation.
5. Producing usable information to measure outcomes that will meet various needs.
6. Achieving and maintaining funding stability.
7. Developing a unified approach and implementing in a consistent manner an abuse/neglect reporting system.

Gary Blumenthal
Executive Director
President's Committee on Mental Retardation
Special Committee on Developmental Disabilities

I would like to take this opportunity to express my appreciation to Chairwoman Jo Ann Pottorff, and the members of the Special Committee on Developmental Disabilities for your gracious invitation to me to address the Committee regarding the activities and priorities of the President's Committee on Mental Retardation.

The President's Committee on Mental Retardation was originally established in 1962, by President John F. Kennedy, as the President's Panel on Mental Retardation, later more formally established by President Lyndon Johnson, in 1966 as the President's Committee on Mental Retardation. Sustained by the support of each Democratic and Republican President since 1966, the Committee's notable achievements include the establishment of State Developmental Disability Councils, Protection and Advocacy Programs, the University Affiliated Programs and an ever changing service delivery system that is expanding away from a single restrictive institutional model towards a new system based upon person based planning embracing individual and family choice, recognizing the individual's strengths and desire for independence.

The PCMR Executive Order specifically directs the Committee to focus our efforts on activities which include supporting prevention initiatives, family and community supports, civil rights

House Select Committee on
Developmental Disabilities
1-25-95 Attachment 4

issues and public awareness. Under the leadership of President Clinton, 14 expert citizens including professionals, parents and self-advocates have been appointed to serve as members of the Committee.

To draw attention to the needs of our constituents, in the current debates that are taking place before Congress and in every State Capitol, the PCMR held a Presidential Forum last April consisting of researchers, service providers, government officials, advocates, self-advocates and family members. The Forum focused specifically on how citizens with mental retardation might be impacted by proposed public policy changes relating to health care, welfare reform, housing, employment, long term care and education.

Our recommendations emerging from that conference are contained in DRAFT FORM in the accompanying document "A JOURNEY OF RENEWAL FOR ALL AMERICANS." The PCMR Draft Recommendations did raise some significant concerns regarding the systemic change underway in most States throughout our nation. In the area of Housing and Employment, the Draft Report is insightful in its discussion of the federal effort to encourage community housing alternatives and integrated competitive employment; however the Draft Report also cites the dissonance between federal rhetoric and federal funding policies which often are at opposite ends, the former supporting aggressive community placement and the latter still providing funding incentives rewarding segregation and isolation.

In the area of public education, the Draft Report cites the significant progress that has been made since 1967 when over one half of our nation's 25,000 school districts denied access to students with mental retardation and other disabilities. Since that time, with the passage of federal education and civil rights legislation, students with disabilities now have federal and state protection that guarantees them a right to an education. We no longer see situations, such as the one faced by my family in the 1960's and 1970's, when Johnson County school officials told my family that my brother was not worthy of receiving a public education. However the Draft Report does make note of serious public policy questions which are being raised regarding the fiscal integrity of special education programs, the movement towards inclusive education and the implications of an academically segregated environment.

The Report also notes the growing concern in Washington and in every State Capitol regarding efficient and effective use of limited and strained federal and state fiscal resources. The President's Committee welcomes this focus and this attention because we firmly believe that the need for fiscal accountability will give further support to our efforts to more efficiently utilize every dollar in a progressive manner.

The next few years will no doubt bring significant debate on each of these issues. In order to facilitate a cooperative and informed relationship between the States and the Federal government regarding the programs that impact citizens with mental retardation, PCMR will maintain an active profile.

The President's Committee will host, over the next five years, a series of Public Policy Collaborative Academies aimed at bringing together State Policy Leaders, Federal Officials, family representatives, consumers and professionals. The PCMR National Collaborative Academy will offer an opportunity for States to receive assistance in learning about best practices, state demographic profiles & rankings, and sources of professional and technical assistance. The Federal Government will have an opportunity to learn of the realities, successes and difficulties of administering state programs, directly from State Policy Makers. States will also have an opportunity to learn about innovative state practices directly from the States involved in these programs. That information will be utilized in a series of recommendations to the President in the PCMR 1995 REPORT TO THE PRESIDENT.

As a former member of this body, and the former chairperson of the National Conference of State Legislatures Task Force on Developmental Disabilities, I particularly look forward to the sharing of valuable information and solutions that States will be able to provide each other in PCMR's National Collaborative Academy. When I served as a Kansas legislator, I clearly remember struggling with the issues of community integration, institutional reduction and the constant effort to protect and improve the quality of existing services. I and many of my colleagues felt a sense of concern that our issues might be unique and not faced by other States. Let me assure you that many States are encountering the same issues facing Kansas; and many States can learn from the example of Kansas' movement towards community integration. In my travels across the country, I have had many opportunities to be introduced to "innovative" programs. I must tell you that it is with great pride that I share with my hosts, my knowledge that the "innovative" programs demonstrated to me have already been in practice in diverse Kansas communities such as Wichita, Lawrence, Pittsburg, Hays, Topeka, Atwood and even Johnson County, to name a few.. That does not diminish the urgency Kansans should feel to continue to improve community programs or to reduce Kansas' overdependence on institutional settings.

Kansas will be invited, through an invitation extended to Governor Bill Graves, to participate in the PCMR National Collaborative Academy. Let me assure you that Kansas will be given <u>full</u> consideration. I appreciate this opportunity to meet with the Committee and I would be happy to respond to any questions.

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
Washington, D.C. 20201-0000

PCMR 1995 NATIONAL COLLABORATIVE ACADEMY ON MENTAL RETARDATION AND RELATED DISABILITIES

BACKGROUND AND PURPOSE:

The President's Committee on Mental Retardation (PCMR) is charged with the responsibility to advise the President and the Secretary of Health and Human Services regarding a broad range of topics relating to mental retardation, including:

1. evaluation of the adequacy of the national effort to reduce the incidence of mental retardation and improve the quality of life for persons with mental retardation;
2. provision of adequate liaison between Federal activities and related activities of State and local governments, foundations and other private organizations; and
3. development and dissemination of information to the public that will help reduce the incidence and ameliorate the effects of mental retardation and related disabilities.

Historically, the PCMR has shared information and networked with an audience comprised of traditional groups, including: mental retardation constituency organizations, allied governmental agencies, advocacy groups, service providers, researchers and educators. With this audience, the Committee has experienced success promoting national support for cutting edge strategies that help achieve PCMR and Presidential goals in mental retardation. There remain inadequacies, however, in the national effort to address problems associated with mental retardation and related disabilities in ways that promote full life-long inclusion of persons with mental retardation in all aspects of community life. The traditional mental retardation/ developmental disabilities and advocacy community is well-informed, and most members of this community share the common value of inclusion. The PCMR is now expanding the audience targeted for its information-sharing, networking and collaborative activities to include non-traditional audiences that influence the success of programs and services to persons with mental retardation and their families.

The Committee is embarking on a bold, creative public education approach. This approach focuses on informing and enlisting ongoing collaborative partnerships with an expanded audience including key State officials, policy makers, and community leaders from the public and private sectors.

The PCMR is planning the first of five annual National Collaborative Academies on Mental Retardation and Related Disabilities, in August of 1995, in Washington, D.C. The Academy theme is "Life-long Inclusion of People with Mental Retardation and Related Disabilities in Community Life." The audience will be comprised of legislators, budget officers and other key State officials, consumers, advocates, service providers, educators, researchers, mental retardation and developmental disabilities administrators, and media experts.

GOALS:

1) provide information and support to States interested in improving the quality of life experienced by people with mental retardation and related disabilities;

2) enhance State participants' knowledge of the social and fiscal benefits of inclusion-based policy and management directions, community programs, and service alternatives; and

3) encourage ongoing collaboration and action within States to include people with mental retardation and related disabilities in all aspects of community life.

STRATEGY:

The activities of PCMR members and staff in planning the National Collaborative Academy are being facilitated by an Advisory Committee comprised of ex officio and at-large members, a sibling of a consumer, and leaders of organizations including, but not necessarily limited to the following:

Best Buddies;
People First;
Self Advocates Becoming Empowered;
Minority Health Professionals;
The National Conference of State Legislatures (NCSL);
The National Urban League;
The National Association of Developmental Disabilities Councils (NADDC);
The National Association of Protection and Advocacy Systems (NAPAS);
The National Association of State Budget Directors (NASBD);
The American Association of University Affiliated Programs (AAUAP);
The American Association on Mental Retardation (AAMR);
The Association for Retarded Citizens - United States (ARC-US);
The National Governors' Association (NGA); and
United Cerebral Palsy (UCP).

Pre-Academy State Consumer Training Seminars and site visits to State mental retardation and developmental disabilities programs and services will be conducted by the State Developmental Councils. The Seminars will train advocates and State participants to assist Academy faculty increase the information-base and sensitivity of State participants regarding effective strategies for achieving full inclusion of persons with mental retardation and related disabilities in community life.

A mental retardation research analyst will collect and analyze current data to produce a profile of each of the six to eight States selected to participate in the Academy. The profiles will address programs and services, trends, and recommendations for improving the quality of life experienced by citizens with mental retardation and related disabilities. Each State team will be provided a copy of its State Profile prior to attending the Academy.

Approximately 100 State representatives will participate in the 1995 Academy. The PCMR will recruit an 8-15 member collaborative team of participants (key officials, including policy makers) from each State. Recruitment will be accomplished in conjunction with local stakeholders who are actively involved in systems change efforts and planning, programs, and services for people with mental retardation and related disabilities. These local stakeholders will function as the "Allied Cooperative Academy Team" representing their State. States will be advised that each State Team should include the following members whose participation will be paid by the Academy sponsors:

two (2) self-advocates;
a family member;
State legislators;
a senior staff member from the Governor's Office;
a leader in the business community;
a director of vocational rehabilitation services;
a director of Special Education;
a State Mental Retardation/Developmental Disabilities Director or a Cabinet official responsible for MR/DD services; and
a representative of the Association for Retarded Citizens (ARC) or a member of an advocacy organization

Other State team members, whose participation will not be financed by the Academy sponsors, may include:

the Superintendent of Schools and/or the director of the local school district;
a representative of University Affiliated Programs;
a representative of the Protection and Advocacy Group;
a representative of the State Association of Counties; and
a representative of the State Developmental Disabilities Planning Council

The 1995 Academy is the first in a series of five annual Academies. Each year thereafter, the Committee will target different audiences for participation in an educational/training seminar similar in objectives, format, and expected outcome(s) to the 1995 Academy.

IMPLEMENTATION DATE AND SITE:

August 11-14, 1995 in Washington, D.C.

PRODUCTS/OUTCOME:

a) A pre-Academy publication presenting an analysis of innovative State programs that support the full inclusion of persons with mental retardation and related disabilities in all aspects of community life;

b. Draft **action-oriented Collaborative State Plans**; and

c. **Draft recommendations** to be included in the **PCMR Annual Report to the President** regarding how Federal and State relationships can be enhanced to reduce incidence rates in mental retardation and related disabilities, improve the quality of life for citizens with these disabilities and their family member, and achieve full inclusion of people with mental retardation and related disabilities in all aspects of community life.

d) Enhanced State Team recognition and knowledge of the social and fiscal benefits of community inclusion, program, service, and management alternatives for people with mental retardation and related disabilities; and

d) Commitment by State Team participants to continued collaboration and working together within their respective states toward this end.

CO-SPONSORSHIPS

The PCMR has shared information regarding the Academy with a broad spectrum of agencies and organizations and invited their co-sponsorship. Commitment to provide support for this important initiative has been received from the following agencies and organizations:

The Administration on Developmental Disabilities (ADD);
The Administration on Aging (AoA);
The National Conference of State Legislatures (NCSL);
The National Council on Disability (NCD);
The National Association of Developmental Disabilities Councils (NADDC);
The National Institute on Disability and Rehabilitation Research (NIDRR);
The Office of Special Education and Rehabilitative Services (OSERS); and
The Office of the Assistant Secretary of the Administration for Children and Families (ACF)

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REPORT TO THE PRESIDENT

The National Reform Agenda and Citizens with Mental Retardation:
A Journey of Renewal for All Americans

Draft Report to the President

U.S. Department of Health and Human Services
Administration for Children and Families

President's Committee on Mental Retardation
Washington, DC

Gary H. Blumenthal
Executive Director

1994

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President's Committee on Mental Retardation Members & Staff
April 1994 Forum Advisory Planning Committee

PREFACE

In April 1994, leaders from the field of mental retardation were gathered together in a forum sponsored by the President's Committee on Mental Retardation (PCMR). They were asked to evaluate the needs of Americans with mental retardation in the context of the Administration's domestic reform agenda. The Report to the President represents the synthesis of the forum's technical papers, deliberations, and analyses in the areas of education, housing, employment, health, welfare, and long-term care. Three core themes bind together the sections of the narrative and accompanying recommendations.

First, there remain great unmet needs. A significant transformation in the nation's care and treatment of its citizens with mental retardation has occurred. However, it is a transformation yet in progress. The report reflects the tension of the juxtaposition of accomplishments against the sense of urgency for critical tasks yet to be completed. For too many Americans with mental retardation, the reforms of the past three decades are merely unfulfilled promises. This is a central theme for the report's discussion of education, housing, and employment.

Secondly, the real revolution will see the end of the premise of dependency that permeates our systems of care and support. This theme is embedded in key concepts throughout the report -- in the principles of choice and control, in the view of persons with mental retardation as citizens and constituents, and in the calls for meaningful inclusion.

The third and final theme is the fundamental importance of individual dignity. It lies at the heart of report's discussion of health care, welfare, and long-term care. The report's recommendations are made against the backdrop of changes in the landscape of American governance since the April meetings. While we understand there are no convenient and readily implemented solutions for these domestic reform challenges, the needs and injustices described in the report will be as pressing tomorrow as they are today. For Americans with mental retardation, domestic reform must remain on the agenda.

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REPORT TO THE PRESIDENT

The National Reform Agenda and Citizens with Mental Retardation:

A Journey of Renewal for All Americans

The President's Committee on Mental Retardation

INTRODUCTION

We stand at a crossroad in the nation's passage into the 21st century. Long-standing assumptions about the relationship of government and citizen in health care, education, employment, and social welfare are being challenged.

The choices made in this national debate will have profound implications for persons with mental retardation. They are among the most vulnerable of American citizens. Like a mirror held before the national renewal effort, the success of reform will be reflected in their lives and well-being.

In the body of the following report, PCMR endeavors to chart the direction of future activities, polices, and strategies for Americans with mental retardation in the context of the President's reform agenda. The assessment represents a distillation of the deliberations and recommendations of leaders in the field of mental retardation during a 3-day PCMR forum in 1994.

Our recommendations are made within the context of the President's domestic reform agenda -- they emanate from the PCMR but reflect the principles of empowerment, equality, and justice as applied to all our nation's citizens.

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I. A PROMISE NOT FULLY REALIZED

> *"Our goals for Katie include wanting her to feel loved, to give her a sense of high self-esteem so that she can experience life with confidence. She is a very social child and while I think she has a great capacity to make friends, I wonder how other children will accept her. We envision her attending public schools and one day hope to see her graduate from high school. I wonder if she will ever get married, and if she doesn't, I hope someday she has a companion to enjoy life with, and if we could we would like to see her remain as happy as she is today."*
>
> Linda Charlton, Maryland

In her address to the PCMR, Linda Charlton described life with her 2-year old daughter, born with Down syndrome. She spoke of her goals and anxieties over what the future holds. In Linda Charlton's statement is the eloquence of parental love and the aspirations of families everywhere -- that our children find opportunity, dignity, and above all, love.

The nation Katie was born into two years ago is far different for Americans with mental retardation from that first described by PCMR in 1967 in its inaugural report, MR 67. The Committee spoke then of the need to provide education, to improve the quality of institutions, to offer rudimentary services in the community, and to grant persons with mental retardation the elementary rights of citizenship.

The Federal Government responded and transformed national policy -- with prohibitions against discrimination on the basis of disability through the Rehabilitation Act of 1973 and the

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Americans with Disabilities Act of 1990, educational mandates in the Education for All Handicapped Children's Act and its amendments, and the institutional reforms and community expansion brought about through Federal legislation and precedent-setting litigation in the Federal courts.

The transformation of national policy affecting people with mental retardation over the past 25 years represents one of the great social reform movements of our time. Policies are now in place at the Federal level that affirm the basic rights and fundamental human dignity of Americans with mental retardation.

And yet, great needs still exist. Aspirations are unfulfilled. Elisha Preston was born 12 years after the publication of <u>MR 67</u>. His mother reflected on the hopes expressed by Linda Charlton -- "I remember taking walks with Elisha when he was an infant. Like any new parent I engaged in lots of idle thought about the future. Those were times of great expectation. I said the same things as Katie's mom. And a decade later my son has had the sweetness and kindness and joy sapped from him by a system and community that has done little but put barriers before him. It makes me want to cry."

Real change and true reform require national leadership. President Clinton proposed a "journey of renewal." In this report, we point out the ways in which this journey will affect Americans with mental retardation. We respectfully ask for your consideration of these recommendations -- recommendations that will transform promises into reality.

II. THE NEW AMERICAN COMMUNITY: OUR SCHOOLS, HOMES, AND PLACES OF WORK

The injustices experienced by people with mental retardation were great in 1967. One half of the nation's 25,000 school districts denied access to children with mental retardation. State-operated institutions, at their peak census of nearly 200,000 residents, were the primary housing option. And the concepts of employment and self-sufficiency were hailed as "revolutionary" in PCMR's inaugural report of that year, which spoke of new ideas and fresh approaches.

Our greatest challenge remains the infusion of new ideas -- ideas that will change, fully and irrevocably, the basic paradigm. Based on exclusion, isolation, and individual deficits, the old service model still stands as an obstacle to true reform. The emerging paradigm is anchored to the values of inclusion, collaboration, and individual determination. Through the Administration's domestic reform agenda, we have the unique opportunity to realize this new vision in the following areas:

- Special education in the United States is a paradox of intent and effect. In order to redress the inequities created by the exclusion of children with a disability from public school, policy-makers inadvertently created a system predicated on segregation. Special education's status as a parallel system must be challenged.

We are a nation of individuals bound together by the vision of community and the sense of purpose defined by our citizenship and what America uniquely represents. PCMR's report to the President is based on this fundamental assumption.

- Since 1967 the nation has reduced its reliance on institutional care while dramatically increasing community-based housing. Yet the fundamental premise of residential care remains unchanged -- persons with mental retardation are the "occupants" of beds and "clients" of services. We must challenge this premise of dependency.

- The success of integrated employment -- real work in real jobs -- is in its acceptance as a true goal for persons with mental retardation. Unfortunately, it is treated as only one alternative along the continuum. We must commit ourselves, totally and wholly, to a vision of equal opportunity in the work place.

- School, housing, and work have been targets of reform efforts since MR 67. In 1967 the preeminent concerns focused on access to public schools, quality of care in the state-operated institutional system, and lost employment potential. While these continue to be points of concern, the mix of issues is far more complex today. It is no longer solely a matter of **where** to locate a service, but rather how to redress the balance of power and choice in the service provider-consumer relationship.

What matters most to people with mental retardation and their families is that which is of importance to all Americans -- to belong to a larger community that endows its members with dignity anchored in a fundamental respect for the individual. We hope that this aspiration, though not fully realized, will find fuller voice in the reforms proposed by the Clinton Administration.

SCHOOL

"I do not want the "retarded corner" of the school."
Linda Preston, Illinois

The adoption of the Education of the Handicapped Act eliminated the exclusion of children with mental retardation from public education. It also created a "special education" system that is separate both in operation and philosophical foundation. This contrived separateness limits opportunities for those within it, and perpetuates inequities and inefficiencies.

The fundamental goal is unchanged from the early years of mandates -- equity in education. Yet the status of education for children with mental retardation is startling in its disparities. Only seven in 100 students with mental retardation spend their school day in classrooms with other children from their neighborhoods. Eleven out of every 100 students do not have access to their community school, attending totally non-inclusive schools.

The basic premises and character of our dual system of education are found to be wanting. It is time to act.

At the heart of the debate is the contemporary utility of the dual system. Does the division of children -- into those who have a disability and those who do not -- continue to serve an educational purpose?

Segregation does not enhance academic achievement and delays social adjustment. It encourages unnecessary labelling of children. It fosters placement on the basis of administrative convenience rather than educational need. How else to explain the arbitrariness of segregation -- that only 35 percent of Vermont's students are educated in separate classrooms compared to 97 percent in Iowa. Why should a special education student in Alabama be eight times more likely to be labeled "mentally retarded" than one in Arizona or New Jersey? Why should an African-American child in the special education system be twice as likely as a white child to be classified as having mental retardation?

Segregation requires the classification of children in order to communicate their "deficits" and to demand narrow instructional specializations of their teachers. What has this classification and specialization achieved? Dropout rates from special education exceed the national average. Post-secondary school unemployment rates approach 50 percent three to five years after leaving school. The segregated system fostered critical access to education in the early years of the mandates, but it bought neither quality nor equity.

Assumptions of the past often obstruct alternative visions of the future. For students in need of specialized education, we must revisit previous assumptions about where those services are delivered.

PCMR RECOMMENDATIONS:
OUR SCHOOLS

The United States achieved access for children with mental retardation. Doors were opened and obstructions overcome. But access has not necessarily translated into equality of education nor quality of outcome. PCMR respectfully requests that you reaffirm the principle of a unified educational system and an end to Federal support for separation. We must unify education for all our children.

THE FEDERAL GOVERNMENT MUST AFFIRM THE PRINCIPLE OF A UNIFIED EDUCATIONAL SYSTEM

- **End the fiscal barriers to inclusion.** Eliminate fiscal incentives for dual systems. Link Federal funds authorized under The Individuals with Disabilities Education Act (IDEA) to total state school population rather than the number of labelled students.
- **Let the children come home.** Eliminate fiscal incentives for out-of-district placements. Federal funds authorized under P.L. 89-313 should be directly linked to each child's home school district.
- **Provide a Federal vision.** Unify and apply the reform agenda across Federal agencies. Federal agencies involved in education should coordinate their training, research, policy, and technical assistance missions. The U.S. Department of Education's Office of Special Education and Rehabilitation Services (OSERS) should make placement-neutral and non-categorical reimbursements to local agencies a requirement of state plans.
- **Set the agenda.** The Federal government should leverage its influence to effect system change. Set the research agenda on unification and inclusion, evaluate the effectiveness of teacher education curricula to facilitate inclusion, and de-emphasize the labelling of "special education" teachers in personnel preparation efforts. Put teeth into the Federal monitoring process. Establish meaningful sanctions for non-compliance.

HOME

"People need to have control of their front door."
T.J. Monroe, Nashville, TN

Rare is the person with mental retardation who experiences "home" as do most Americans. Beyond the family home, the major housing alternatives are institutional and other group facilities, owned and controlled by others, with people they never chose to live with. They are denied the experience of a "place of one's own" -- an aspiration common to all Americans.

Contemporary options are still largely limited to "homes" that are owned or leased by states, private organizations, foster care programs, board and care providers, or non-profit housing corporations. While we speak of dignity, rights, and inclusion, the sobering fact is that most people with mental retardation living away from their family homes are under the control of other people. Basic models of care are predicated on dependence and the absence of choice.

PCMR recognizes the moral and legal rights of persons with mental retardation to experience and shape their lives as citizens and as individuals, including the most fundamental right -- to decide where and with whom they will live.

Owning or renting a home of their own choice (excluding those living in their family home) is currently limited to 8.4 percent of the 347,000 persons with mental retardation receiving services. For the vast majority of people with mental retardation, housing and support services are bundled as "packages" based on group considerations and agency preferences rather than individual needs. The individual in need of supports is often compelled to live in settings where the needed services are provided or, conversely, to receive unnecessary care in exchange for residential support.

Recognition of the consumer's right and capability of home ownership is not without basis in recent experience. People with mental retardation can and do own and rent their own homes all through the U.S. Though little used to date, this is the most rapidly growing type of residential option. In localities across the nation, innovative funding options are being implemented. State governments, including Colorado, Connecticut, Florida, Illinois, New Hampshire, Michigan, New York, Rhode Island, and Vermont, have developed innovative financial assistance programs for cash assistance, leases, rent subsidies, and vouchers.

David Guillet just purchased a condominium in Cumberland, Rhode Island. Formerly a resident of group homes, he, together with his parents, Marge and Lou, were pioneers in the development of home ownership options in the State. Through a collaborative effort of state agencies, they obtained a low-interest mortgage and a grant for the down payment, closing costs, and furniture. Compared to publicly-funded group homes, often with service packages that are not needed and associated staffing expenses, home ownership may be less expensive.

"My son has very severe disabilities," said Mrs. Guillet, "quadriplegic, legally blind, with severe seizures. Yet, I have the same fears for David as I do for my other children who do not have disabilities. We are helping David expand his relationships by introducing David to the fire department, to his immediate neighbors, by holding an open house. The neighbors were wary, assuming the State had purchased the condo. Their perceptions immediately changed when they found out that David was the owner, not some "ward" of the State.

"We have choices now. We pick the support staff. David has complete control of the choices in his life. David can eat what he wants to eat, when he wants to eat. If he wants to wear a blue shirt with green shorts, that's OK. I can see the difference in his eyes."

The great challenge is to see beyond current service paradigms. Many people with mental retardation who receive residential services live in housing in which services and personal assistance are developed around group considerations and agency preferences rather than individual needs and choices. People with mental retardation are often wrongly viewed by government agencies and service providers as needing "special housing," rather than as individuals with idiosyncratic needs for support.

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Changes in Federal policy will be crucial to the development of consumer-controlled housing. The Federal Government has considerable leverage through its housing programs, income support policies, and public information efforts. Through modifications of these programs, the Federal Government can play an affirmative, leading role in housing reform for people with mental retardation.

PCMR RECOMMENDATIONS: OUR HOMES

Twenty-seven years after the onset of deinstitutionalization in 1967, we continue to house an unconscionably large number of American citizens in large non-inclusive settings. Residential housing and financing models across the range of residential options remain largely predicated on institutional concepts of care and training. We recommend that the Federal Government should affirm the principles of choice and control in housing policy for people with mental retardation.

THE FEDERAL GOVERNMENT MUST AFFIRM THE PRINCIPLES OF CHOICE AND CONTROL

- **Separate housing from supports.** People should have stable homes while fully exercising their right to choose the agencies and individuals who enter those homes to provide supports. Federal and local policy should affirm the separation in all programs specifically funding services or housing.

- **Speak with a vision.** Develop a broad-based inter-agency approach to housing. Unify and coordinate Federal efforts to affirm the principles of choice and control. This can be achieved through: (1) a coordinated initiative on personal housing through the Departments of Health and Human Services and Housing and Urban Development; (2) a modification the Federal commitment of HUD Section 8 rental assistance to include mortgage assistance; and (3) fiscal support of public information programs -- change will be facilitated at the local level when consumers, family members, and advocates know what options are available.
- **Act on a vision.** Establish consistent housing policies across Federal agencies. The Federal Government can directly facilitate choice and control through modification of existing policy: (1) by permitting recipients of Disabled Adult Child (DAC) or Social Security Disability Insurance (SSDI) benefits (without Supplemental Security Income or SSI) who are eligible for Home and Community Based Services to retain their full DAC or SSDI benefits while receiving waiver services; (2) by permitting people in means-tested programs to save towards home down payments or apartment deposits; (3) by allowing waiver funds to be applied to supplemental housing costs where SSI and available state supplements fall below standards; and (4) by increasing the size and flexibility of housing subsidy programs for impoverished persons with mental retardation.

- **Encourage states to do what they do best -- innovate.** Fund, support, and develop systems change projects. Experimentation is a hallmark of state systems; facilitate the transition from facility-based care to supported community living through fiscal assistance projects, and collaborative efforts with private financing agencies.

WORK

"Work in a sheltered workshop and make money -- like 79 cents every 2 weeks."

Tia Nelis, Illinois

In its 1967 Report to the President, PCMR estimated that the potential annual earnings lost because of unnecessary unemployment among persons with mental retardation ran into the billions of dollars.

The 1983 PCMR report concluded, "...there are hundreds of thousands of mentally retarded people who are employable but are unemployed because of misconceptions . . ." The report asked us to raise our expectations.

Today, after a decade of raised expectations, we can point to years of achievement, of research, and of model demonstrations in communities across the nation. Persons with mental retardation have affirmed over and over again PCMR's

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central belief in their capacity to be productive workers. Tens of thousands have participated in innovative employment programs in real work settings. The Federal Government has infused the principle of equal work opportunity in every piece of disability-related Federal legislation since 1973. Above all else, the decade of demonstration has raised our expectations.

Yet the contemporary employment status of Americans with mental retardation is one of underachievement. A decade after we proclaimed a "decade of progress" in the 1983 report, unemployment rates among adults with mental retardation exceed 70 percent. Why should this be? Why is unemployment such an intractable problem given what we know -- that thousands of persons considered unemployable years ago are now working in real jobs in real work settings?

The weight of Federal and state funding remains largely devoted to segregated services -- 80 cents of every state dollar reimburses segregated rehabilitation services; 90 cents of every Federal dollar support segregated services. While research clearly demonstrates the efficacy of integrated employment, state service systems remain deeply entrenched in segregated models of rehabilitation. Integration in employment is made more difficult by inconsistent Federal regulatory policies, some of which restrict the opportunity for real employment. Work incentive reforms, for example, recently enacted for supplemental security income beneficiaries do not apply to SSDI and disabled adult child (DAC) recipients with mental

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retardation. For these individuals, employment endangers benefits, even at poverty level wages. In the absence of transitional support, entry into the world of work is fraught with personal risk.

Despite legislative intent, systems of employment training remain bound to funded "slots" into which people must fit. Given the bias of the system, the alternatives, if they exist, are limited. Seven out of 10 persons served in rehabilitation programs are either in separate or non-work day activity type settings. We must personalize supports, let consumers control funds to direct their own programs, and select the types of supports needed. We must create the options so that choices are available.

Seventy percent of persons served in day and employment programs are served in segregated programs; 90 cents of every Federal dollar supports these segregated services.

The goal of real employment and equal opportunity seems almost as distant today as in 1967 or 1983. Though we now know the vision can be realized in practice, the challenge is to make it a reality for more than a select few. Large entrenched systems do not change so readily. We recommend support for greater economic independence for persons with mental retardation.

PCMR RECOMMENDATIONS: WORK

Workers with mental retardation have repeatedly demonstrated their ability to be employed for decent wages with benefits. Like a distant beacon, competitive employment shines as brightly as ever, but across a sea of exclusion and unemployment. PCMR recommends bringing Federal regulatory and fiscal policies into line with Federal principles and ending Federal support for exclusion in the work place.

SUPPORT THE PRINCIPLES OF CONSUMER INVOLVEMENT, CHOICE, AND CONTROL WITH FEDERAL REGULATORY REFORMS.

- **Bring Federal spending into line with Federal principles.** Require the U.S. Department of Education's Rehabilitation Services Administration (RSA) funding (including Section 110 funds and the required state match) to be employed in support of integrated employment; change financial controls so that consumers exert control over expenditures. Use RSA leverage to modify state agency goals.
- **Make the system accountable.** Monitor the implementation of the Rehabilitation Act Amendments to assure that consumers are offered services in real work settings and involve them in all stages of program planning. Ensure the adherence of state and local school systems to the employment goals of The Individuals with Disabilities Education Act.

- **Build capacity.** Choice requires options. Use Federal demonstration funds to stimulate innovations in achieving integrated employment and support replication projects. Ensure the participation of youths with mental retardation in the Administration's school-to-work transition initiatives.
- **Establish consistent policy across agencies.** Remove limitations on the use of Medicaid for integrated employment; ensure involvement of persons with mental retardation in the many employment and economic development initiatives of the Federal government.

III. THE DIGNITY OF OUR CITIZENS: HEALTH, WELFARE, AND LONG-TERM CARE

In the journey of national renewal we must give priority to reforming those systems that contradict fundamental American values of equality and self-determination. The Clinton Administration has elevated these contradictions to the center of the national debate in health, welfare, and long-term care. How these debates are resolved will be critical to the security of America's citizens, in particular those with mental retardation.

Health care reform is a principal priority of PCMR. Americans with mental retardation and their families are especially vulnerable to the effects of discrimination in the health care system. Our struggle will not end until universal coverage is achieved. We concur with the President that "...the

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human cost far outweighs the risk of responsible change."

Welfare serves many purposes. Above all else, it must support self-sufficiency, productivity, family, and those who cannot care for themselves. Americans with mental retardation are disproportionately affected by pervasive and long-term poverty, unemployment, or long-term dependency. They have very much to gain and very much to lose in the outcomes of the nation's welfare reform. **We must be sure that the interests of people with mental retardation and their families are not lost in the clamor for change.**

Long-term care is a critical ingredient of a comprehensive domestic agenda. The long-term care agenda recommended by PCMR is likewise a critical element in any effort to provide a secure future for people with mental retardation and their families. **The domestic reform agenda is incomplete without a guarantee of home and community-based long-term supports.**

The outcomes of domestic reforms are critical to the well-being and dignity of all Americans. PCMR requests that the needs and the special vulnerability of Americans with mental retardation not be overlooked in the pending reforms.

HEALTH

"*No band-aids, real health care reform for all.*"

Health care reform campaign button

"Seven years ago when Robert was 2 1/2 years old, he started having epileptic seizures. Due to the seizures, Robert is mentally retarded and at times unable to walk or talk. At the time he first became ill, Tom was a first year apprentice with the Sheet Metal Workers Union. Our insurance coverage was 80 percent with 20 percent to be paid by the member. During that period we accrued several tens of thousands of dollars worth of medical bills. As we were a struggling, young two-income family making $20,000 per year, we applied for assistance, only to be denied -- because we were, "just over the maximum income allowed." After six months the insurance company stopped paying for a nurse to help with Rob. I was forced to quit working. We sold the house and took all the equity to pay off the medical bills. The move required Tom to spend four hours on the road each day going to and from work. Robert's illness made him uninsurable because he now had a "preexisting condition," and we became all too aware of how important it was for Tom to keep his job. After the move more admissions followed, and again the bills started mounting. It was at that time we were told to apply for Children's Medical Services. If it were not for this organization we would have been homeless. In October of 1992 our renewal came due and we were denied services based on our income being in excess of the $22,000 per year maximum. Last year Tom's company was forced to cut back to a 4-day work week. Due to Robert's preexisting condition Tom is locked into his job, even if his employer cuts him back to a 3-day work week. The problems are neverending. Two years ago while lifting Rob, I hurt my back. The injury has left me bedridden and unable to care for Robert many times since. It was one of these times I contacted the local agencies, to get some help taking care of Rob in our home. I was told that if he was on Medical assistance they could send an aide, but because he was ineligible, all they could offer was to institutionalize him.

A moral imperative is non-negotiable. PCMR believes that health care is a basic

"I informed them that I would not even consider putting Rob in an institution, and that he would not thrive without the love of his family nor would we. In an institution no one is going to get up during the night, while he is having seizures, and let him know that it's "ok" and that mom loves him. No one in an institution could ever give him the love that we give him at home. This is why we so desperately need health care reform. What has happened to us and many other families like ours is wrong."

Kate Miles, Maryland

Americans with mental retardation and their families are painfully aware of the health care crisis. Their needs are a microcosm of the national crisis. Their voices are part of a larger chorus of Americans with disabilities and their families and of the tens of millions of other citizens with no coverage or inadequate and inferior care in the world's most advanced nation. PCMR's position has an essential predicate -- that health care is a basic right of all Americans. We support your courageous effort to "undertake this journey of change" towards a just and equitable health care system for all.

Like other Americans, persons with mental retardation are remarkably diverse in their health care needs. They cannot be treated as a single constituency. Most have the same basic needs as everyone else. But they have a special vulnerability which is the legacy of discrimination, unemployment, and poverty. Many adults with mental retardation are often disqualified for Medicaid because their disability is not "severe" or because they are too proud to apply, yet the jobs they can find are usually marginal or part time. As a result they are without the continuity of health care that they particularly need. For these individuals and their families there is a crisis of coverage.

For others, there are complex medical problems and significant health care needs. These individuals have disorders associated with rare or low incidence syndromes, or challenging behavior problems requiring health care professionals with specialized training. Meeting their needs has been complicated by shifts in models of care. Those most severely impaired are now living longer because of medical advances and their numbers are increasing because of improved health care during infancy and childhood. The locus of health care services for this population is in the community. But there is a severe shortage of providers with even the rudimentary expertise in working with individuals with mental retardation. For these individuals, there is a crisis of care in the community.

What do Americans with mental retardation need? Policies affirming guaranteed health coverage that directly address the inequities and arbitrariness of the current care system: universal coverage, limits on out-of-pocket expenses, access to specialists, elimination of work disincentives, and home and community-based long-term services, including personal assistance services.

PCMR RECOMMENDATIONS: HEALTH

For Americans with mental retardation, there is a dual health care crisis -- shrinking coverage and a dearth of skilled practitioners in the community. Both must be addressed. The following recommendations address universal coverage, service delivery, and financing.

Like all journeys into uncharted regions, the nation's passage will be marked by false starts, unexpected turns, and illusory conclusions. For persons with mental retardation and their families, the endpoint of the health care reform battle is clearly marked.

TRUE HEALTH CARE REFORM MUST INCLUDE UNIVERSAL AND COMPREHENSIVE COVERAGE

- **Do not discriminate.** People with mental retardation must be able to participate fully in the nation's health care system, regardless of age, health, disability status, or income. **Permit no exclusions based on pre-existing conditions.**
- **Be comprehensive.** People with mental retardation must have access to a health care system that ensures a comprehensive array of health, rehabilitation, personal, and support services across all service categories and sites of service delivery. **Provide access to specialists and other providers.**
- **Serve the person not the system.** Ensure the appropriateness of health services. People with mental retardation and their families must be assured that comprehensive health, rehabilitation, personal, and support services are provided on the basis of individual need, preference, and choice. **Allow meaningful consumer involvement, accountability, and provision of home and community-based long-term care.**
- **Be equitable.** People with mental retardation and their families must be assured equitable participation in the nation's health care system and not be burdened with disproportionate costs. There cannot be financial disincentives for serving people with more intensive needs for health services and other supports. **Limit out-of-pocket costs and eliminate lifetime caps on benefits.**

- **Be efficient.** People with mental retardation and their families must have access to a health care system that provides a maximum of appropriate, effective services that includes effective cost controls as well as a minimum of administrative waste. **Remove work disincentives in health coverage policies.**
- **Do not exclude.** True health care reform must integrate, not segregate, health services for persons with mental retardation. In the reform of the nation's health care systems, we must vigilantly adhere to the intent of the Americans with Disabilities Act. Ensure equal access. Policies and procedures may not, by design or impact, deny individuals with mental retardation health services by reason of their disability. Rationing, or denial of coverage, or unintended discriminatory effects of neutral policies are violations of the intent of the law.
- **Build capability.** Prepare service providers and service consumers. Health care providers, including family physicians, need knowledge, experience, and models. Much exclusion occurs not because of lack of skills but because of lack of experience. Similarly, persons with mental retardation and their families must be made aware of their options and rights.
- **Build capacity.** High quality primary care must be available to all, at all ages. Home health care services must be available.
- **Do not eliminate options currently available.** Referral to specialist care must be an option within the generic system. For people with atypical medical needs, "comprehensive" services must include referral to the most relevant specialists.

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WELFARE

"It defies our values as a nation."
President Clinton's 1994 State of the Union Address

Welfare in its present form presents a challenge for persons with mental retardation -- economic self-sufficiency, equal opportunity, family support, and above all the dignity and respect that come with being a contributing and productive citizen. The welfare system can foster personal assets limitations that discourage savings towards future needs. There is a penalty on parents, brothers, sisters, and other family who assume the responsibility of care, even when few viable alternatives exist. Its regulatory structure discourages integration into the work force. PCMR believes an effective system of social welfare should promote the independence of people and reduce their long-term dependence over time. Let people work and save and encourage family support.

Persons with mental retardation are participants in the full range of social insurance programs -- as workers contributing taxes to Social Security, as dependents and survivors entitled to draw on the Old Age, Survivors, and Disability Insurance (OASDI) and Social Security Disability Insurance (SSDI) Trust Funds, and as recipients of means-tested income assistance. It is to those who are most economically vulnerable that PCMR addresses its concerns and recommendations.

There is a fine line between reform and neglect; in our reforms we must do no harm to those most vulnerable.

Two pillars of Federal poverty-related income assistance to persons with mental retardation are the Supplemental Security Income (SSI) program and the Aid to Families with Dependent Children (AFDC). PCMR supports the Administration's scrutiny of AFDC; we urge you to also include changes in the SSI program in the larger welfare reform agenda. SSI plays a central role in the modern configuration of mental retardation services. Benefits now reach more than 700,000 Americans with mental retardation under 65 years of age. Contradictions between social goals and statutory regulations within SSI have long been the object of criticism. The SSI Modernization Panel noted several problems: regulations that discourage personal savings, the harshness of in-kind support penalties on family care, and earned income exclusions that make the transition from welfare to work extraordinarily difficult for potential wage earners with mental retardation. We strongly support the recommendations of the SSI Modernization Project Panel: bring Federal benefit standards in line with our national goals.

PCMR is concerned about the outcomes for persons with mental retardation and their families in the current welfare reform debate. While changes are needed, it is important to consider carefully how any modifications will affect those for whom work mandates are inappropriate. For recipients with mental retardation there is a narrow line between the objectives of welfare reform and unintended neglect. Federal data indicate a rate of functional disabilities among women in the AFDC

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population to be in the 20 percent range. In addition, some 19 percent of households receiving AFDC benefits have another disabled adult or child present. Of the total AFDC enrollment of 14.1 million, an unknown but potentially large number have mental retardation. In short, many AFDC recipients, children as well as adults, have disabilities and are truly dependent.

In total numbers and potential impact, Americans with mental retardation have a significant stake in the course of welfare reform. In our effort to correct the wrongs of the system, we must not forget those most vulnerable. Do no harm. We urge sensitivity to the unique needs of welfare recipients with mental retardation.

PCMR RECOMMENDATIONS: WELFARE

PCMR believes that an effective social welfare system is an investment in human capital. The central reform issue is the use of welfare for the realization of potential. We concur with the Administration that the central objective of welfare reform is to bring today's systems of support into congruence with core American values.

ENGAGE FEDERAL POLICY TO SUPPORT THOSE GOALS MOST VALUED BY AMERICANS WITH MENTAL RETARDATION: SELF-SUFFICIENCY, OPPORTUNITY, FAMILY, AND PERSONAL DIGNITY

- **Encourage savings and self-sufficiency.** Increase the assets limits under SSI to encourage savings and security; end the practice of penalizing trivial assets such as interest on bank accounts; allow savings for special purposes.
- **Support the family.** Eliminate the penalty for "in-kind support and maintenance" provided by families caring for their adult sons and daughters with mental retardation.
- **Stop punishing those with mental retardation who want to work.** Income support must not be predicated on total dependency; extend the Earned Income Tax Credit to households without children.
- **Leverage existing jobs programs.** There are effective existing Federal employment programs that could benefit persons with mental retardation; expand their programmatic focus.

Welfare reform should not forget those who are most vulnerable. We conclude by again underscoring the importance of anticipating any negative consequences of welfare reform proposals for people with mental retardation and their families: mothers, children of single parents, those unable to enter the work force, and older adults. Reform must work for all Americans.

LONG-TERM CARE

Disability is a natural dimension of the human condition. It can touch any life at any time and for many Americans it is manifested as a lifelong need for support. Among this group are significant numbers of Americans with mental retardation. While the composition and character of long term care is in a state of continuous evolution, we can address the basic features that impact most significantly on persons with mental retardation.

The existing Federal supports for long term care services for Americans generally have been characterized as a $70 billion system that is fragmented and ill-matched to the needs of current recipients. It has a medical bias that results in persons going without services or receiving more intensive services than necessary. These critiques are no less valid when applied to the long-term care needs of persons with mental retardation and their families.

What Americans with mental retardation and their families desire is both more and less than the current system delivers, derived as it is from its institutional precursor. The agenda in long-term care is both a composite and a constituent part of the reform debates on employment, health care, housing, and welfare. What is desired of long-term care is an extension of what is needed generally from our reform efforts -- greater independence, choice, dignity, and inclusion.

To understand the texture of the contemporary long-term care system for Americans with mental retardation one must understand its historical antecedents in the state-operated institutional care system. Over two decades ago Federal Medicaid dollars were used to finance improvements in the state institutions and to create additional capacity in the private sector. Beginning with the Home and Community Based Services (HCBS) waiver in 1981, diversion of Medicaid funds was authorized for community placements of individuals who might otherwise have qualified for an Intermediate Care Facility-Mental Retardation (ICF-MR) bed. Thus it was through the open-ended Medicaid ICF-MR program that states expanded long-term residential alternatives outside of the traditional state-operated institutional system.

We must be cognizant of the role that Medicaid plays in the support of Americans with mental retardation. Realize also that it has been both a bane and bulwark.

We must be cognizant of the enormity of the Medicaid program in the lives of persons with mental retardation. Revisions in policy will dramatically affect the character of services. Medicaid ICF-MR and Home and Community-Based Services funds represent the single largest Federal services program in the field. For over 20 years, its institutional component has grown dramatically. Because of its size and institutional origins, Medicaid is both bulwark and bane to long-term care. The funds are a cornerstone of funding in the field.

When matched with mandated state and local funds, Medicaid accounts for 52 percent of all financial resources for mental retardation services nationally. Nevertheless, for all the Federal legislative and administrative language expressing commitment to independence and inclusion in the community, only 1.5 percent of this enormous annual Federal investment is used for individualized supports for people with mental retardation.

Needs for long-term care are significant and will grow through the decade. Waiting lists for placements into residential facilities are estimated in excess of 78,000. There are also over 40,000 nursing home residents with mental retardation; many will require transfer to more appropriate settings. There is a large population of adults supported at home with aging parents increasingly unable to provide care. Finally, there are those 228,000 persons in state institutions and other congregate facilities with over 6 beds for whom more individualized supports are required.

Our concerns in long-term care are mirrored in our recommendations for housing. Despite the contraction of the institutional network, and despite the dramatic growth of individualized supports in the community, the non-inclusive character of the nation's residential services for persons with mental retardation remains fundamentally unchanged. Ending this segregation is our first priority. We must realign the nation's fiscal commitments to bring this about. Federal funding policies must be modified to eliminate fiscal incentives that encourage development of more institution-like care in separated facilities of all sizes. We must bring coherence to long-term care; it must be predicated on the individual not the facility, on personal needs and not professional guilds, on consumer choice rather than service "slots."

PCMR underscores again the interconnectedness of the domestic agenda for Americans with mental retardation. Health housing, and welfare reform will not be complete until the long-term care needs are systematically and comprehensively accounted for.

PCMR RECOMMENDATIONS: LONG-TERM CARE

The long-term care agenda for persons with mental retardation is inextricably linked to our reform recommendations in health, housing, welfare, and work. Each is a critical component to long-term care. What is presented below is not a recitation of new and additional services but rather a recommendation for a coherent approach to long-term supports based on the President's call for "People First."

COMMIT FEDERAL POLICY TO THE PRINCIPLES OF INDEPENDENCE AND COMMUNITY LIFE

- **Permit the states to innovate.** Federal commitments to instititutional services spending through Medicaid ICF-MR are

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enormous, yet we continue to cap the level of Medicaid benefits available for serving people in their own homes. Make the Medicaid Home and Community Based Services a full Medicaid option. Regularly provide residents of ICFs-MR the option to use the Medicaid HCBS Waiver. Permit Medicaid Waiver funds to be used to supplement housing costs.

- **Provide universal access to individualized long-term care supports through social insurance.** Provide reasonable cost sharing through modest deductibles and co-insurance; uphold personal dignity and self-direction; minimize dislocation; provide only that which is specifically appropriate to the individual; avoid forced impoverishment.
- **Put people first.** Long-term services must commit to a non-facility based model of care; address the needs of the individual and break free of the "continuum" of care funding options.

IV. EPILOGUE: PUTTING PEOPLE FIRST

The contours of mental retardation in America changed significantly in the 27 years since MR 67. Yet inequities remain, and basic paradigms of care are unchanged. PCMR's recommendations are a challenge to these old assumptions.

Our recommendations must be viewed as mere threads in the larger fabric of an individual's experience. Reform is more than the identification of "optimal" services; what we do cannot be disentangled from the meanings, experiences, and aspirations of the individuals that all these systems of supports are intended to serve. The essence of reform in the field of mental retardation lies in an abiding respect for the person. We are talking about constituents, not clients; citizens rather than recipients -- let us not lose sight of the person in the policy.

"We went to a forest preserve one weekend," recalled Linda Preston. "A group of young adults had an impromptu concert with bongos, drums, and other instruments. We went over to listen. One of them gave Elisha some maracas. And for the next hour, Elisha was just one of the band, making music, dancing and keeping the beat. They didn't see his disabilities. They just saw the music in him."

This is the crossroad. In our journey of national renewal, we must choose to challenge the old assumptions. We must move the nation towards a vision that accords a basic dignity to all its citizens. Let America's fundamental nobility be reflected in the lives of those like Elisha Preston, Katie Charlton, David Guillet, and Robert Miles. Their passage is a journey we will all share.

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PCMR Conference

A larger delegation of self-advocates participated as delegates and speakers during the recent PCMR Presidential Forum, and met with Health & Human Services Secretary Donna Shalala.

by Bena Smith

The President's Committee on Mental Retardation (PCMR) recently hosted a Presidential Forum: The President's Reform Agenda and People with Mental Retardation: 21st Century Realities on April 24-26, 1994. The conference was held to provide a forum for selected national leaders in the field of mental retardation and related developmental disabilities to discuss how citizens with mental retardation and developmental disabilities would be impacted by reform initiatives in health care, welfare, long term care, employment, education and housing.

Bena Smith is the Public Awareness Subcommittee Coordinator for the President's Committee on Mental Retardation in the Administration for Children and Families.

Focusing on the President's and the Administration's belief in "People First," PCMR, ACF, and the Department of HHS made a major effort to achieve this goal by including a significant number of self-advocates and family members as keynote speakers and active participants in the forum deliberations. Self-advocates who participated were nominated by two national self-advocate organizations, People First and Self-Advocates Becoming Empowered.

For her presentation at the luncheon on April 25, 1994, Secretary Donna Shalala received a standing ovation for stating that the time had come to recognize the contributions of self-advocates and family members. She noted that President Clinton

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Report

would soon appoint the first self-advocate to the PCMR. She also stressed the Administration's deep belief that every citizen's contribution should be valued, and quoted President John F. Kennedy who called upon Americans to "integrate people with mental retardation within our modern society...We do not have the luxury of wasting our human resources."

The following excerpts by the self-advocates and parent representatives set the tone of empowerment and respect for each individual citizen with mental retardation and developmental disabilities:

T. J. Monroe - Self-Advocate, Vista Volunteer with People First of Tennessee. Mr. Monroe is responsible for providing leadership and technical assistance to 10 regional self-advocacy groups and assisting with four additional groups.

Mr. Monroe's comments: " I know you are experts in this field because of your schooling, training, family and professional experiences. I am also an expert in this field because of my first hand experience: living in institutions and the community; fighting for a good education; getting a real job; searching for good health care; struggling to pay my bills; looking for long term support; and speaking up for my needs and my rights to lawmakers.

"I think what we need to do is bring together professionals' knowledge and self-advocates' personal experience. This way, we can build a plan for action that solves the real problems people have. Self-advocates want to become empowered and have a voice in solving the problems they experience. Together with professional and government resources, we can make it work."

T.J. Monroe, Nashville, Tennessee, recently appointed by President Bill Clinton as the first self-advocate member of the PCMR, served as a Presidential Forum keynote speaker.

Tia Nelis - Self-Advocate, Wayne, Indiana - Co-Chair, National Steering Committee of the Self-Advocates Becoming Empowered. Ms. Nelis works for the University of Illinois, Chicago, on the aging project for people with disabilities and for the People First of Illinois.

"What I am hoping is that the President's Committee on Mental Retardation will look at the areas and issues that include people with disabilities, and all those areas to be a part of those decisions, and those processes that you are going through, because who knows better than the people themselves."

Koquese Collins - Secretary to the Mayor of Detroit, Michigan - Mother of an eleven year old son with Down Syndrome

Ms. Collins' comments: "When I received a call from the Director of the Arc in Detroit asking me if I would be willing to speak on my experience as a single parent of a child with a disability, my initial response was why me? Shouldn't you find someone better qualified to speak before such an important audience? But then I realized that my experiences as a parent of a child with a disability, though in many ways similar, were indeed, uniquely different from the experiences of parents of children who are without special needs.

"You have an enormous responsibility, for you will help shape the services, supports and ultimately the very quality of life afforded my son Brian and others like him into the twenty-first century and beyond. I could not allow an opportunity to speak on behalf of the Brians, the Sarahs, and the Jasons — the people with disabilities — to simply pass me by.

"My son, Brian is 11 years old, has Down Syndrome, and is classified as educably mentally impaired and trainably mentally impaired. But more importantly, Brian is an active compassionate and extremely friendly young man. I am constantly amazed by this child who in so many ways is wise beyond his years. Brian is the third of my five children. His siblings are without disability. Brian realized he is

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different, as do his brothers and sister. In our family though, Brian's disability has really become secondary. He is my son, a brother, playmate, friend, family.

"I guess you could characterize our household as an inclusive environment that works. Our dynamic, of course, is not without difficulties. I dream of the best futures possible for all my children. I fear, however, that ignorance, bias and the inability to see people with disabilities as people first, not Brian's disability itself, will stall Brian. Today, I sit before you in an attempt to ensure that doesn't happen."

Don and Dawn Merriman - Salina, Kansas - Don is a heating and air-conditioning engineer for Salina Supply Co. - Dawn is employed as a parent information coordinator at the Occupational Center of Central Kansas. Both parents are involved with advisory committees, rehabilitation facility committees, initiative planning councils, their local Arc and legislative advocates for disability issues. - Parents of a 14-year-old son, Craig.

"We are here today because we are parents of a 14-year-old son named Craig. He is our only child, and we are proud parents. In files and on paper you will see words like profoundly retarded, cerebral palsy, seizure disorder, nonverbal and severe and multiple disabilities. This is how the systems that provide services to Craig describe him. As parents and people who are close to Craig, you will hear us describe him in a very different manner. Craig has a zest for life like no one else we know. He loves doing anything with his dad, loves race cars, being outside shooting baskets, riding in convertibles and trucks, the Three Stooges, and going to middle school dances.

"Life with Craig has never been dull. In his first 14 years of life he has spent more time in hospitals having surgeries and tests and medical procedures than most people will spend in a lifetime. Our world quickly became one of hospital emergency rooms, frequent hospital stays, orthopedic surgeries, blood levels, special education and fear of what tomorrow might bring. There has been a lot of pain for Craig and for his family. There have also been many joys and many accomplishments for Craig and his family.

"One of our major accomplishments is being here at this convention today. We dream of a day when the gaps are eliminated, and there is truly a continuity of services. We dream of a day when families are asked, "Tell us what you need." We dream of the day when people really listen. We know that when people listen change can and does become a reality.

Linda and Lincoln Charlton - Bel-Air, Maryland - Parents of a two-year-old daughter, Kaitlin Aubrey, born with Down Syndrome.

"Two years ago, we became the first-time parents of a baby girl, Kaitlin Aubrey, who was born with Down Syndrome. While this was a heart-breaking and unanticipated outcome, we're grateful for the tremendous support we received — from family, friends, health professionals and educators — as we ourselves become 'educated' on what it means to have a child with special needs...a continual learning process.

"Katie has always been an alert child...ever watching all that goes on around her. She began early intervention services at three months of age and now also receives speech therapy during which she is also learning sign language. She has been in good health overall these past two years. While it's still too early to know what level she will function at in later years, we try to set no limits for her, and give to her the same experiences we would to any child of ours.

Ann Forts, Center Harbor, New Hampshire, attended the Presidential Forum and distributed buttons reflecting her upbeat attitude about Down Syndrome.

"She loves people, music and animals and is very social. While we read a lot about Down Syndrome, mental retardation and other disabilities to learn what others have experienced, how they've handled different situations, etc.—our best coping mechanism seems to be Katie herself. Her smiles, good nature and continued progress enable and encourage us to keep working with her to master different skills.

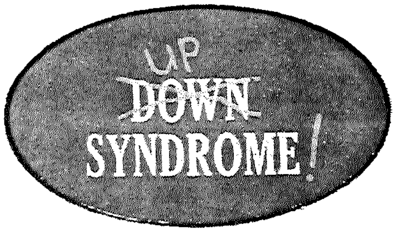
"Like all parents, we want the best for our daughter. Our hope for Katie is that she will grow up feeling very much loved by us, the rest of her family and friends. However, we also worry about her future...her acceptance in the community, the schools she will one day attend, and much later, employment opportunities.

"From a philosophical standpoint, having a child with special needs changes one's priorities; from a practical standpoint, it can also have an economic impact. And emotionally, there will always be some sadness about what 'won't be' for Katie and for us, but

'As I have observed people with disabilities who have attended the Forum, I keep wonde in my head what my daughter will be like at their age, and if she too might one day attend such an event or be a self-advocate. I've learned to keep my expectations high for her."

as we move forward that is no longer the first concern.

" As I have observed people with disabilities who have attended the Forum, I keep wondering in my head what my daughter will be like at their age, and if she too might one day attend such an event or be a self-advocate. I've learned to keep my expectations high for her."



An overall evaluation obtained from participants of the Presidential Forum indicated that this was a rare and unique experience and that participants look forward to the PCMR continuing to include self-advocates and parents of citizens with mental retardation and developmental disabilities in all of their future conferences. To this end the PCMR has made a self-commitment to continue the inclusion of self-advocates and parents to help accomplish the Administration's objective of placing "People First."

(Below) Family participants at the Presidential Forum shown meeting with HHS Secretary Donna Shalala. (From left to right): Dawn Merriman, Don Merriman, Salina, Kansas; Donna Shalala; Brian Washington, Detroit, Michigan; Linda Charlton, Lincoln Charlton, Bel Air, Maryland; and Koquese Collins, Detroit, Michigan.

4-53

KPC DD

Kansas Council on Developmental Disabilities

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

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

TO: Members of the House Select Committee on Developmental Disabilities

FROM: Jane Rhys, Executive Director JR

DATE: January 24, 1995

RE: DEFINITION OF DEVELOPMENTAL DISABILITIES AND POLICY

Attached is the definition of Developmental Disabilties under which the Kansas Council on Developmental Disabilities operates. I have also attached our suggestion, requested by Representative McKechnie, for language to include in a policy or bill regardiong the Kansas position on individuals with developmental disabilities. I would be happy to proide any explanation or justification for the suggested language and I thank you for the opportunity of testifying and providing this language.

House Select Committee on
Developmental Disabilities
1-25-95 Attachment 5

5-1

What are Developmental Disabilities?

Public Law 103-230, as amended, the Developmental Disabilities Assistance and Bill of Rights Act of 1994 defines a developmental disability as:

A severe, chronic disability of a person five years of age or older which -

- is attributable to a mental or physical impairment or combination of mental and physical impairments, and,
- is manifested before the person attains age twenty-two, and
- is likely to continue indefinitely; and
- results in substantial functional limitation in three or more of the following areas of major life activity:
    - Self-care
    - Receptive and expressive language
    - Learning
    - Mobility
    - Self-direction
    - Capacity for independent living; and
    - Economic self-sufficiency, and
- reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated; except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

Kansas Policy For Developmental Disabilities

*Suggested Language

The State of Kansas believes that Kansans with developmental disabilities, including those with the most severe disabilities, are capable of achieving independence, productivity, integration, and inclusion into the community. To achieve these things Kansans with developmental disabilities and their families must have the opportunities and support necessary to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to the life of their communities and the State of Kansas.

It is the responsibility of the State of Kansas, in partnership with Kansas service providers, and the United States Government, to assist individuals with developmental disabilites and their families to receive supports, services and other assistance in a manner that demonstrates respect for each individual's dignity, personal preferences, and cultural difference.

Kansans with developmental disabilities and their families are the primary decision-makers regarding the supports and services they need and must play decision-making roles in politics and programs which affect their lives.