



Families Together, Inc.

Parent Training & Information Centers for Kansas

Home Page:
<http://www.families-togetherinc.org>

Administrative Center
313 N. Seneca
Wichita, Kansas 67203
Voice/TDD (316) 945-7747
1-888-815-6364
Fax (316) 263-0031

Wichita Parent Center
3033 W. 2nd, Suite 106
Wichita, KS 67203
Voice/TDD (316) 945-7747
1-888-815-6364
Fax (316) 945-7795
wichita@families-togetherinc.org

Topeka Parent Center
501 Jackson, Suite 400
Topeka, KS 66603
Voice/TDD (785) 233-4777
1-800-264-6343
Fax (785) 233-4787
topeka@families-togetherinc.org

Garden City Parent Center
1518 Taylor Plaza
Garden City, KS 67846
Voice/TDD (620) 276-6364
1-888-820-6364
Español (620) 276-2380
Fax (620) 276-3488
gardencity@families-togetherinc.org

Kansas City Parent Center
1333 Meadowlark Ln., Suite 103
Kansas City, KS 66102
Voice/TDD (913) 287-1970
1-877-499-5369
Fax (913) 287-1972
kansascity@families-togetherinc.org

Statewide Spanish Parent Line
1-800-499-9443

Representative Kiegerl and members of the Children and Families Committee:

I am Connie Zienkewicz, Executive Director of Families Together, Inc. Families Together is a non-profit organization which serves Kansas families who have children with disabilities or special health care needs. We are dedicated to a society that includes and values all people. It is our mission to encourage, educate and empower families and their sons and daughters with disabilities to be effective advocates. We currently are the recipients of the Parent Training and Information Center grant from the Federal Department of Education to assist families in understanding and navigating the Special Education system, and the Family to Family Health Information Center grant to assist families of children and youth with special health care needs to find their way through the maze of health care. In addition, we also have contracts with Social and Rehabilitation Services, Kansas Department of Health and Environment, and the Kansas Department of Education to help each of those agencies serve families of children with disabilities or special health care needs.

At Families Together, we talk to families every day who are facing the challenge of finding appropriate services for their children in schools, the health care system and in their communities. Each year our staff members provide direct services to over 2500 families across the state. We have a newsletter that reaches about 10,000 families and the electronic version of the newsletter is sent to an additional 3000 parents and professionals in the field of education or other services to this population.

HOUSE CHILDREN AND
FAMILIES
DATE: JANUARY 27, 2011
ATTACHMENT NO.2

Assisting Parents and Their Sons and Daughters with Disabilities

One of the greatest concerns to the families we serve is support for their family in providing for the needs of their family member with a disability and the other members of the family. One way that the state has created to help families and individuals with disabilities is the Home and Community Based services waivers for persons with Developmental Disabilities, Head Injury, Physical Disabilities, and Severe Emotional Disabilities. These waivers have assisted families in getting appropriate services for their sons and daughters in their local communities instead of the institutional placements of the past.

In recent years, the funding for services on these waivers has not kept pace with the numbers of persons living in our communities in Kansas. Currently there are **1413** children under the age of 18 on the waiting list. That means that all those families are trying to meet the needs of all their family members without any support. Since services to children are provided by families and children are generally is served in schools 7 hours a day, the services for children on the waiting list has not been addressed with the same vigor as those adults who do not have ANY services after graduation from school. The impact this has on families is that they do not have the respite to take a break from the day to day care-giving of the person with disabilities, the child or young adult does not have the support that they may need to access their community more independently, the siblings of the person with disabilities may not have the opportunity to access as many activities due to the care-giving responsibilities of the parents. This added stress on families makes it much more likely that a child with disabilities will be a victim of abuse than a child without disabilities. The rate of abuse or neglect of children with disabilities is 3.4 times that of typical children. (Consortium of Citizens with Disabilities, now called the Office of Child Abuse and Neglect)

From SRS: As of January 6, 2011, we have 3391 persons on the MR/DD waiting list who have a request date of 12/31/2010 or earlier. Of the 3391, 2383 are unserved, 1008 are underserved. Breakdown by ages is: 5-17: 1413, 18-64: 1965, 65+: 13

By providing training and support to families, Families Together works to decrease the stress on families and support their appropriate care and supervision of the care of their child with disabilities. Some of the ways that we support families include weekend training events for the entire family, phone and in person consultation with our staff about the concerns of the family, and materials and training for families, professionals in the Child Welfare system, and caregivers.

On a personal note, my husband and I are the parents of six children one of whom is a young lady with severe disabilities. She is 25. Fifteen or so years ago, we applied for the HCBS DD Waiver for her. She has received services in our home from caregivers since she was about 8. When she graduated from high school 4 years ago, she began receiving services due to her status as being "in crisis" since her dad and I were both working all day. She is on the waiting list for residential services at this time. The last time I checked she was about 2000 on the 4000+ waiting list for additional services. Currently she continues to reside with us in our family home with the support of Supportive Home Care workers. She is fortunate to have a family who can continue to care for her in the family home. Other adults are not so fortunate and must rely on elderly parents/caregivers to do what they can to provide a good safe environment for them.

Many families who need services now to support their children in their home are on that same LONG waiting list. This probably means that other children in the family don't have parents to attend their parent teacher conferences, little league games, or take them to the park because the parent is the caregiver for sibling with disabilities or special health care needs who cannot attend. This is a challenge for the parents who would like to be there to watch or support their other child, and for the sibling who needs the time and attention of the parents, as well. These added stresses contribute to the dissolution of families and to the possibility of abuse and neglect of some of all of the children in the family.

In addition to the inadequate funding for Community programs, the Education budget is being strained in Kansas school districts and across the country. Our school districts need adequate funding to provide the services to help our children – all children – to become the next leaders of our state. Making our schools the best they can be in preparing all children for a productive future should be another priority of this legislative session. In the area of Special Education, families and students need to see employment as the FIRST option for life after school. Many students with disabilities are not given that vision, but rather one of "being cared for" or no hope of a "REAL" job in our communities. Students and families need to help the schools to prepare for competitive employment with real success. When we help persons with disabilities to be tax payers instead of users of state dollars, we grow our economy, and more importantly we give dignity to the persons who are successful in their adult lives.

As a society and as a state, we need to find ways to support young families with the assistance they need to meet the needs of all members of the family. This little bit of support for families can reduce stress, add quality to marriages, and decreases the likelihood of abuse and neglect.

Thank you for the opportunity to provide you with this information today.

Connie Zienkewicz, Executive Director

Wichita Parent Center
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Wichita, KS 67203
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1-877-499-5369 toll free

Statewide Spanish Parent Line
Lina Estratal de Padres en Espanol
1-800-499-9443

Administrative Center
313 N. Seneca, Suite 114
Wichita, KS 67203
Call the Wichita Center above

How Families Together Offers Assistance

The Parent Training and Information Centers in Wichita, Topeka, Garden City, and Kansas City provide literature, videos, and information on a variety of topics, such as:

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

Families Together sponsors two state-wide conferences each year. Nationally known speakers gather with families, educators, and service providers to share successes and achievements and to provide information on current issues of interest.

Families Together provides a voice for families with the state legislature. Families Together offers free workshops for parents whose children have disabilities and the professionals with whom they work. Examples of the workshops are Special Education Law, IEP Development, Step Ahead at Age Three, Discipline, and Effective Advocacy.

A newsletter is distributed quarterly to families, service providers, and education advocates who have requested to be on the Families Together mailing list.

Parents may call or come by any of the centers for individual assistance from other parents of sons and daughters with disabilities. Events including mini-conferences, Parent Networking Conferences and Family Enrichment Weekends are held statewide to provide opportunities for parents to learn and network with each other.



Yes, please add my name to the Families Together mailing list to receive the quarterly newsletter and send additional information regarding the Child Advocate Program.
(Free printed copy of newsletter to families, professionals \$10 annual subscription—free to professionals by email)
Yes, I am interested in serving as Child Advocate.

Name _____ Parent _____ Service Provider _____

Address _____ (City) _____ (Zip) _____

Telephone () _____ If no phone, how can you be reached? _____

Name of child with a disability _____ Date of Birth _____

Child's disability _____ Date of Birth _____

Other children in the family _____ Date of Birth _____

_____ Date of Birth _____

Mail this form to: Families Together, Inc. • 501 Jackson, Suite 400 • Topeka, KS 66603

Supporting parents and their sons and daughters with disabilities for more than 25 years.



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Additional Programs

Family-to-Family

The Kansas Family-to-Family Health Information Center (F2F HIC) helps families of children and youth with special health care needs (CYSHCN) and the professionals who serve them. Because the health care needs of CYSHCN are chronic and complex, parents and caregivers are often challenged with finding the resources to provide and finance health care for their children. Staff at the Kansas F2F HIC understands the issues that families face, provides advice, offers a multitude of resources, and taps into a network of other families and professionals for support and information.

The Board of Directors and staff members are parents of sons and daughters with disabilities, consumers, siblings and advocates who believe that all students are entitled to support services. Through a variety of programs that Families Together, Inc. offers, parents are informed about available resources and services throughout the state. They have information about making the maximum use of the services needed to support their son or daughter, so that their children can realize their capability and pursue a full and satisfying life.



Families Together, Inc. is part of Project Number CFDA Nu. 84.328M Award No. H328M070001 from the US Department of Education, Special Education Programs, Department of Personnel Preparation

What is Families Together?

Families Together, Inc. is a statewide Education Advocate program through a contract with the Kansas State Department of Education. This program serves children whose parents are unknown, unavailable or whose parent rights have been terminated and the child needs someone to represent them in special education matters. Families Together, Inc. is dedicated to a society that includes and values all people. They offer families the security of belonging to a support network of other parents that face similar goals, challenges, and needs.

The Board of Directors and staff members are parents of sons and daughters with disabilities, consumers, siblings and advocates who believe that all students are entitled to support services. Through a variety of programs that Families Together, Inc. offers, parents are informed about available resources and services throughout the state. They have information about making the maximum use of the services needed to support their son or daughter, so that their children can realize their capability and pursue a full and satisfying life.

Additional Programs

Education Advocate Program

Families Together coordinates the Education Advocate program through a contract with the Kansas State Department of Education. This program serves children whose parents are unknown, unavailable or whose parent rights have been terminated and the child needs someone to represent them in special education matters. Families Together and the Kansas Department of Health and Environment have developed a Child Advocate training Program to serve infants and toddlers with disabilities whose parents are unknown, unavailable or whose parental rights are terminated.

Child Advocate Program

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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. Parents can also utilize the program for any other situation in which they feel the need for additional support, such as transition periods, medical issues, and more.