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Family Support and Information Organizations for Families of Children with Special Needs

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Organization Name	Web address	Description
The American Self	www.selfhelpclearinghouse.org	Provides information on finding and developing self-
Help Clearinghouse		help groups for a range of health and disability
		issues
The Arc of the US	www.thearc.org	A national organization of and for people with
		developmental disabilities and their families.
	www.arcut.org	
Alliance of Genetic	www.geneticalliance.org	A partnership of self-help groups and professionals
Support Groups		addressing communication, service delivery, and
		advocacy issues for member support groups that
		are composed of individuals and families affected by
		genetic disorders
The Beach Center	www.beachcenter.org	The Beach Center on Families and Disability at The
		University of Kansas
Disability Resources	www.disabilityresources.org	Provide links to the best disability resources on the
		web, including national and international sites,
		documents, databases, and other informational
		materials.
Exceptional Parent	www.eparent.com	Publishes monthly magazine for parents of children
Magazine		with disabilities and professionals providing services
		to children and families. The Exceptional Parent
		website affords parents an opportunity to connect
		with other parents around similar family and
		disability issues.

Organization Name	Web address	Description
Family Village	www.familyvillage.wisc.edu	A family-friendly website that provides informational
		resources about specific disabilities and resources,
		and opportunities to be in touch with others with
		similar issues.
Family Voices	www.familyvoices.org	A national grassroots organization directed by
		parents of children/adults with special health care
	www.utahfamilyvoices.com	needs, and composed of families and professional
		friends who care for and about children with special
		healthcare needs
Federation of	www.ffcmh.org	A national parent-directed organization focused on
Families for		the needs of children and youth with emotional,
Children's Mental		behavioral, or mental disorders and their families
Health		
Mothers United for	www.netnet.net/mums/	Provides support to parents of a child with any
Moral Support		disability or rare disorder in the form of a networking
National Parent to		system that matches them with other parents whose children have the same or a similar condition. A
Parent Network		national/international database of families enables
(MUMS)		MUMS to match parents who have not been able to
		find match at the local or state level
National	www.nichcy.org	A national clearinghouse for families and
Dissemination Center	www.money.org	professionals that offers information about
for Children with		disabilities and related services, assists with
Disabilities (NICHCY)		referrals, produces state resource sheets that
		provide contacts for disability related services and
		programs in each state, and publishes a newsletter
National Fathers	www.fathersnetwork.org	Provides information, support, and resources to
Network		fathers of children with disabilities or chronic illness.
		Supporting the efforts of 83 fathers' programs in the
		US, the National Fathers Network publishes a bi-
		yearly newsletter, a monthly column in Exceptional
		Parent magazine, and operates a web page

Organization Name	Web address	Description
National Organization for Rare Disorders (NORD)	www.rarediseases.org	Provides information about rare disorders and brings families with similar disorders together for mutual support. Single written copies of disability
		information sheets are available through a literature order form
National Respite Locator Service	http://www.archrespite.org/index.htm	Maintains a database of respite services for those looking for childcare for children with special needs. The Family Village
PACER Technical Assistance Alliance for Parent Centers	www.taalliance.org www.utahparentcenter.org	Parent Training and Information Centers (PTIs) in each state provide training and information to parents of infants, toddlers, children, and youth with disabilities and to professionals who work with children. This assistance helps parents to participate
		more effectively with professionals in meeting the educational needs of children and youth with disabilities.
The Sibling Support Project	http://www.siblingsupport.org/about/about-don-meyer	A national program dedicated to the interests of brothers and sisters of people with special health and developmental needs.

Information developed by:

Utah Family Voices

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