



Where Do I Start?

Resources for Parents & Children with Disabilities or Special Health Care Needs

Between the alphabet soup of disability labels, laws and regulations--CP, DS, IEP, ADA, IDEA, 504--and all the different agencies that serve families with sons and daughters with disabilities--P2P, PEAK, PEP, CDE, Arc, CCB--well, it can get a little confusing! Here is a quick guide to some major resources and what they provide.

<p>P2P: Parent to Parent of Colorado</p> <ul style="list-style-type: none"> • One to one parent matching • Listserv linking parents throughout the state • Up-to-date information and referral, quarterly newsletter • Resource packed website including support group listing, parent wisdom 	<p>1-877-472-7201 p2p-co.org</p>
<p>The Arcs in Colorado</p> <ul style="list-style-type: none"> • If you are looking for an advocate, start with your local Arc • The Arc of Colorado has a list of statewide Arcs on their website 	<p>1-800-333-7690 thearcofco.org</p>
<p>Assistive Technology Partners</p> <ul style="list-style-type: none"> • Device exchange program, database of potential AT funding resources • Make and Take directions on various low-cost AT adaptations and devices • Community based demonstrations, annual conference 	<p>1-800-255-3477 uchsc.edu/atp</p>
<p>CCA: Colorado Citizens for Accountability</p> <ul style="list-style-type: none"> • Patient safety information and referral • Advocacy training for those who have family members in the hospital • Support for families/individuals dealing with legal issues in the medical system 	<p>303-226-5526 coloradocitizensforaccountability.org</p>
<p>CCDC: Colorado Cross-Disability Coalition</p> <ul style="list-style-type: none"> • Information and assistance on disability rights issues for youth and adults • Advances legislation and public policy impacting the disability community 	<p>303-839-1775 ccdconline.org</p>
<p>CDE - ESLU: Colorado Department of Education - Exceptional Student Leadership Unit</p> <ul style="list-style-type: none"> • Website resources on special education law, school/district programs, etc. • FAST FACTS on a variety of topics • Information on educational specialists, parent-professional partnerships 	<p>303-866-6694 www.cde.state.co.us/index_special.htm</p>
<p>DDD: Division for Developmental Disabilities and CCBs: Community Centered Boards</p> <ul style="list-style-type: none"> • Provides various services to individuals with developmental disabilities • Administers children and family programs, adult programs • Information on CCBs (designated as the single entry point into long-term service and support for persons with developmental disabilities) 	<p>303-866-7450 www.cdhs.state.co.us/ddd</p>
<p>Easter Seals Colorado</p> <ul style="list-style-type: none"> • Respite, including Discovery Club, weekend programs and summer camp • Warm water therapy and aquatic programs • Employment services/support, transition trainings, transportation assessments 	<p>303-233-1666 x237 eastersealscolorado.org</p>
<p>EI Colorado: Early Intervention Colorado (formerly ECC)</p> <ul style="list-style-type: none"> • Connects families with early intervention services to help infants and toddlers under age three grow and develop, and to help their families in this process 	<p>1-888-777-4041 eicolorado.org</p>

<p>El Grupo VIDA</p> <ul style="list-style-type: none"> Information, referrals and support groups for Spanish speaking parents Free annual fall conference in Denver 	<p>303-904-6073 elgrupovida.org</p>
<p>EMPOWER Colorado</p> <ul style="list-style-type: none"> Support, education and advocacy for families of children and youth with mental health issues Support groups throughout the state; statewide listserv connecting families Educational classes for families and professionals 	<p>1-866-213-4631 empowercolorado.com</p>
<p>Family Voices</p> <ul style="list-style-type: none"> Advocacy for children with special health care needs Assists families in navigating health systems including Medicaid, Medicaid waivers and private insurance Training, information, referral, policy, parent friendly website resources 	<p>1-800-881-8272 familyvoicesco.org</p>
<p>Guardianship Alliance of Colorado</p> <ul style="list-style-type: none"> Information and referral on guardianship, including a volunteer guardianship matching program Information and training for those wishing to become a guardian for a family member who is 18 or older 	<p>303-228-5382 guardianshipallianceofcolorado.org</p>
<p>HCP: Health Care Program for Children with Special Needs</p> <ul style="list-style-type: none"> Information and referral to services and supports including Medical Home, screening, clinics, financial assistance Regional offices throughout Colorado 	<p>303-692-2370 hccolorado.org</p>
<p>PEAK: Colorado's Parent Training and Information Center</p> <ul style="list-style-type: none"> Statewide parent advisors who provide information about the special education process and parent's rights Trainings on a variety of topics including Understanding IEPs Inclusion resources and annual conference for parents and school personnel Online calendar of events throughout the state 	<p>1-800-284-0251 peakparent.org</p>
<p>PEP: Parents Encouraging Parents</p> <ul style="list-style-type: none"> Free conference, lodging and meals included, held twice per year at various statewide locations (apply early as waiting lists occur frequently) Brings together parents and professionals for education on supporting your child in school and community 	<p>303-866-6846 cde.state.co.us/cdesped/PEP.asp</p>
<p>The Legal Center for People with Disabilities & Older People</p> <ul style="list-style-type: none"> Advice on the legal rights of people with disabilities Publishes Everyday Guide to Special Education Law 	<p>1-800-288-1376 thelegalcenter.org</p>



So where do you start, who do you call?

Still confused? First of all, don't give up. Let Parent to Parent help you get pointed in the right direction. Give us a call. We are all in this together.

Other information sheets in this series:
 Where Do I Start? Disability Specific Resources
 Available for downloading at p2p-co.org



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 Parent to Parent of Colorado
 1-877-472-7201

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Where Do I Start? Disability Specific Resources

Parents of children with disabilities frequently request information and support regarding a particular disability. Below is a list of Colorado disability specific organizations that offer resources, information and, in some cases, parent support groups.

We have also included major national organizations which may provide materials in Spanish, online forums or a list of support groups by state. *Please call P2P or visit our website for additional resources.*

P2P: Parent to Parent of Colorado, p2p-co.org, 877-472-7201

- One to one parent matching
- Website with additional disability specific resources and parent support groups
- Listserv linking parents throughout the state

Autism/Asperger Syndrome

- Autism Society of Colorado, autismcolorado.org, 720-214-0794 or 866-733-0794
- Autism Society of Boulder County, autismboulder.org, 720-272-8231
- Larimer County Autism Society, autismlarimer.org, 970-377-9640
- Pikes Peak Region, Autism Society of America, asappr.org, 719-216-7175
- Autism Society of America, autism-society.org, 800-328-8476
- M.A.S.K. - Mother's of Asperger's Syndrome Kids, hometown.aol.com/maskas99 (online forum)
- Online Asperger Syndrome Information & Support (O.A.S.I.S.) aspergersyndrome.org

Brain Injury

- Brain Injury Association of Colorado, biacolorado.org, 800-955-2443
- Brain Injury Association of America, biausa.org, 800-444-6443

Cerebral Palsy

- Cerebral Palsy of Colorado, cpco.org, 303-691-9339
- Cerebral Palsy Association of Colorado Springs, cpappr.org, 719-638-0808
- United Cerebral Palsy, ucp.org, 800-872-5827

Chromosomal Disorders

- The XYY Project, xxyysyndrome.org, 303-400-3456
- Chromosome Deletion Outreach, chromodisorder.org/CDO, 561-395-4252
- National Fragile X Foundation, nfxf.org, 800-688-8765

Down Syndrome

- Colorado Springs Down Syndrome Association, csdsa.org, 719-633-1133
- Mile High Down Syndrome Association, mhdsa.org, 303-797-1699
- National Down Syndrome Congress, ndsccenter.org, 800-232-6372

Epilepsy

- Epilepsy Foundation of Colorado, epilepsycolorado.org, 303-377-9774 or 888-378-9779
- Epilepsy Foundation, epilepsyfoundation.org, 800-332-1000

Fetal Alcohol Syndrome

- NOFAS Colorado, nofascolorado.org, 303-692-2620
- National Organization on Fetal Alcohol Syndrome, nofas.org, 800-666-6327

Hearing and Vision Impairments

- Colorado Families for Hands and Voices, handsandvoices.org/chapters/colo.htm, 303-492-6283
- American Council of the Blind of Colorado, acbco.org, 888-775-2221
- Anchor Center for Blind Children, anchorcenter.org, 303-377-9732
- Colorado School for the Deaf and Blind, www.csdb.org, 719-578-2100
- National Federation of the Blind of Colorado, nfbco.org, 303-778-1130 or 800-401-4632

Infantile Scoliosis

- Infantile Scoliosis Outreach Program (ISOP), infantilescoliosis.org, 303-691-9339 or 866-417-4873

Learning Disabilities/Dyslexia

- Learning Disability Association of Colorado, ldacolorado.com, 303-894-0992
- LD Online, ldonline.org
- National Center for Learning Disabilities, nclcd.org, 888-575-7373
- Rocky Mountain Branch of International Dyslexia Association, dyslexia-rmbida.org, 303-721-9425
- International Dyslexia Association, interdys.org, 410-296-0232

Mental Health

- Empower Colorado, empowercolorado.com, 866-213-4631
- Federation of Families for Children's Mental Health - Colorado, coloradofederation.org, 888-569-7500
- Mental Health America of Colorado, mhacolorado.org, 800-456-3249
- National Alliance for the Mentally Ill, Colorado, namicolorado.org, 888-566-6264
- Depression and Bipolar Support Alliance, dbsalliance.org, 800-826-3632
- Child and Adolescent Bipolar Foundation, bpkids.org, 847-256-8525

Spina Bifida

- Spina Bifida Association of Colorado, coloradospinabifida.org, 303-797-7870

Tourette Syndrome

- Tourette Syndrome Association Rocky Mountain Region, tsarmr@att.net, 720-212-7535
- Tourette Syndrome Association, tsa-usa.org, 718-224-2999

For information on additional specific disabilities, we recommend:

- CHADD (Children & Adults w/ Attention Deficit/Hyperactivity Disorder), chadd.org, 800-233-4050
- Muscular Dystrophy Parent Project, parentdmd.org, 800-714-5437
- Parents of Premature Babies, preemie-l.org
- Sensory Processing Disorder Foundation, spdnetwork.org, 303-794-1182

For general information on disabilities from national organizations, we recommend:

- MUMS National Parent-to-Parent Network, netnet.net/mums, 877-336-5333
- National Dissemination Center for Children with Disabilities (NICHCY), nichcy.org, 800-695-0285
- National Organization for Rare Disorders (NORD), rarediseases.org, 800-999-6673 (voicemail only)

Other information sheets in this series:

Where Do I Start? Who Do I Call?
(English and Spanish)

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