



DSAGSL RESOURCE GUIDE

LOCAL MULTI-SERVICE AGENCIES AND ORGANIZATIONS

Albert Pujols Wellness Center for Adults with Down syndrome stlukes-stl.com/services/wellness-center/index.html

Down Syndrome Association of Greater St. Louis (DSAGSL) dsagsl.org

Down Syndrome Group of the Ozarks ozarksdsg.org

Down Syndrome Guild of Greater Kansas City kcdsg.org

DSAGSL Community Groups dsagsl.org/programs-resources/community-groups

Midwest Easter Seals lifeskills-stl.org

Missouri Recovery Network morecovery.org

Paraquad paraquad.org

People First Missouri missouripeoplefirst.org

Pujols Family Foundation pujolsfamilyfoundation.org

St. Louis Arc slarc.org

Transition Council and Alliance transition4life.org

ILLINOIS AGENCIES AND RESOURCES

Arc of IL thearcofil.org

Central Illinois Down Syndrome Association cidso.org

Designs for Change www.designsforchange.org

Family Matters Parent Training and Information Center fmptic.org

Heart of Illinois Down Syndrome Association hoidsa.org

Illinois Department of Human Services dhs.state.il.us/page.aspx?item=29728

Illinois Life Span illinoislifespan.org

IMPACT CIL impactcil.org

Lincoln Land Down Syndrome Society lldss.org

STAR NET starnet.org

GOVERNMENTAL AGENCIES

Missouri Department of Mental Health Regional Offices <https://dmh.mo.gov/dev-disabilities/regional-offices>

Missouri Disability Portal disability.mo.gov

Missouri Department of Social Services dss.mo.gov

Missouri Governor's Council on Disability disability.mo.gov/gcd

Social Security Administration: ssa.gov

St. Louis Office for Disability Resources <https://www.stlidd.org/>

NATIONAL ORGANIZATIONS

American Association of People with Disabilities aapd.com

Family Voices (Children's Health Care) familyvoices.org

Dads Appreciating Down Syndrome dadsnational.org

Down Syndrome Affiliates in Action dsaia.org

Down Syndrome Information Network down-syndrome.org

GiGi's Playhouse Down Syndrome Awareness Centers gigisplayhouse.org

National Association for Down Syndrome nads.org

National Down Syndrome Congress ndscenter.org

National Down Syndrome Society ndss.org

PRENATAL RESOURCES

Lettercase lettercase.org

Global Prenatal Testing Pamphlet downsyndrometest.org

National Down Syndrome Adoption Network ndsan.org

National Down Syndrome Society ndss.org/Resources/New-Expectant-Parents/Understanding-a-Diagnosis-of-Down-Syndrome/

Reece's Rainbow Adoption Grant Foundation reecesrainbow.org

LOW COST MEDICAL SERVICES

Free and Low Cost Car Seats

Kohl's for Kids at Cardinal Glennon Hospital <http://www.glennon.org/programs/kohls-4-kids-program/> or call

Kohl's Safety Store at University of Missouri Health System <https://www.glennon.org/what-we-do/safety-program/> or 573-875-9216

Illinois County Health Departments <https://www.dph.illinois.gov/local-health-departments> (find your county) or call 217-782-4977

Missouri County Health Departments health.mo.gov/living/lpha/pdf/printablelisting.pdf (find your county) or call 573-751-6170

Safe Kids Illinois safekids.org/coalition/safe-kids-illinois or call 312-227-6696

Safe Kids Missouri safekids.org/coalition/safe-kids-missouri or call 573-522-2820

Safety Stop at St. Louis Children's Hospital stlouischildrens.org/health-resources/community-education/safety-stop or 314.454.KIDS (5437) or 800.678.KIDS (5437), then press 3

Basic Health Care

MO Health Net dss.mo.gov/fsd/mchild.htm

Dental

Low Cost Dental Clinics, Missouri Dental Association - <https://www.modental.org/public-resources/free-and-low-cost-dental-care>

Low Cost Dental Clinics, Greater St. Louis Dental Society - www.gslds.org/clinics.php

Vision

Eye Care America eyecareamerica.org/eyecare/care/index.cfm

Specs For Us: Precision Eyewear for Special Children specs4us.com

Hearing

Missouri Commission for the Deaf and Hard of Hearing mcdhh.mo.gov/

SPECIALTY MEDICAL AND THERAPY SERVICES

Children's Hospital (St. Louis) Down Syndrome Center stlouischildrens.org/our-services/down-syndrome-center

Dynamic Pathways <https://www.dpioh.com/>

Family Therapy Solutions <http://ftsolutions.org/>

Ranken Jordan rankenjordan.org

Sensory Solutions, LLC sensorysolutions.org

Therapy4Kids <http://www.therapy4kidsllc.com>

Therapeutic Horsemanship thstl.org

Therapy Relief therapyrelief.com

AGING AND ALZHEIMER'S DISEASE

Alzheimer's Association alz.org/dementia/down-syndrome-alzheimers-symptoms

National Institute of Health <https://www.nia.nih.gov/health/alzheimers-disease-people-down-syndrome>

Association on Aging with Developmental Disabilities agingwithdd.org

Knight Alzheimer's Disease Research Center at Washington
U knightadrc.wustl.edu

National Down Syndrome Society ndss.org/Resources/Aging-Matters

DUAL DOWN SYNDROME-AUTISM DIAGNOSIS

Down Syndrome Autism Connection ds-asd-connection.org

Understanding Intellectual Disabilities and
Health intellectualdisability.info/diagnosis/downs-syndrome-and-autistic-spectrum-disorder

Kennedy Krieger Institute kennedykrieger.org/more-down-syndrome-parents-view

Down Syndrome Education Online down-syndrome.org/updates/341/updates-341.pdf

National Down Syndrome Society ndss.org/Resources/Health-Care/Associated-Conditions/Dual-Diagnosis-of-Down-Syndrome--Autism/

MENTAL HEALTH / BEHAVIOR SERVICES

Department of Mental Health/St. Louis Regional Office <https://dmh.mo.gov/dev-disabilities/regional-offices/stlouis>

Bridges Community Support Services, Inc. bridgescss.com

Mental Health America of Eastern Missouri <https://www.mha-em.org/>

Mental health services dmh.mo.gov

Dynamic Pathways <https://www.dpioh.com/>

Therapy4Kids <http://www.therapy4kidsllc.com>

CLINICAL /RESEARCH INFORMATION

Centers for Disease Control and Prevention <cdc.gov/ncbddd/birthdefects/DownSyndrome.html>

LuMind Foundation <lumindfoundation.org>

Medline Plus <nlm.nih.gov/medlineplus/downsyndrome.html>

National Institute of Health (USA) <https://www.nichd.nih.gov/health/topics/downsyndrome>

SPECIFIC MEDICAL TOPICS IN DS

Breastfeeding a Child with Down Syndrome, by the Nursing Mothers Assoc. of Australia

<breastfeeding.asn.au/bf-info/down>

Breastfeeding and Down Syndrome, by the La Leche Organization

<lalecheleague.org/fag/down.html>

Center for Motor Behavior in Down Syndrome <umich.edu/~cmbds>

Dental Care in Down Syndrome: A Review of the Literature by Sindoor Desai, DDS

<riverbendds.org/index.htm?page=desai.html>

Down's Heart Group <dhg.org.uk>

Growth Charts for Children with Down Syndrome <growthcharts.com>

My Brother and Me: about Down Syndrome and Alzheimer's

angelfire.com/mi4/downs_dementia/index.html

ASSISTANCE FOR LOW INCOME FAMILIES

Catholic Services <www.ccstl.org> - 367-5500; 4532 Lindell Blvd., St. Louis, Mo. 63108

Circle of Concern <www.circleofconcern.org> - 636-861-2623; 112 St. Louis Ave., Val ley Park, 63088

Kingdom House <www.kingdomhouse.org> - 421-0400; 1321 S. 11th Street, St. Louis, 63104

Midwest Special Needs Trust <midwestspecialneedstrust.org>

Salvation Army <www.salvationarmy.org>; 646-3000; 1130 Hampton Ave., St. Louis, 63139

St. Patrick's Partnership <https://stpatrickcenter.org/>; 802-0700; 1200 N. 6th St. , St. Louis, 63106

St. Vincent DePaul Society <https://svdpstlouis.org/>; 531-2183 or call 531-SVDP (7837)

EDUCATION ADVOCACY

Advocates for Special Education

https://www.advocatesforspecialeducation.com/search_results

Family Advocacy and Community Training factmo.org

Legal Services of Eastern Missouri Children's Legal Alliance <https://lsem.org/childrens-legal-alliance-program/#:~:text=The%20Children's%20Legal%20Alliance%20program,be%20champions%20for%20their%20kids.>

Missouri Protection and Advocacy Services moadvocacy.org

MPACT <https://www.missouriparentsact.org/>

Wrightslaw wrightslaw.com

EDUCATION

Affordable College Online affordablecollegesonline.org

Belle Children's Services of St. Louis Arc slarc.org/site/441/belle_childrens_services.aspx

College/Continued

education https://www.ssdmo.org/step3/Supports_for_College.html

DESE Special Education (Youth) dese.mo.gov/se

Education Plus edplus.org

Good Shepard School for Children goodss.org

National Association for Child Development nacd.org

Promise Christian Academy promisestl.org

Special School District ssdmo.org

Think College thinkcollege.net

UMSL SUCCEED Post-Secondary Program umslsucceed.com

U.S. Department of Education ed.gov/index.jhtml

IEP RESOURCES

Transition and the IEP https://www.ssdmo.org/step3/Transition_Planning_IEP.html

TECHNOLOGY

C-wide: Dolphin Trips c-wide.net

Flash Master (Math tutoring device) flashmaster.com

ipads 4 Kids with Special Needs

https://www.amazon.com/gp/product/0985168005?pf_rd_p=d1f45e03-8b73-4c9a-9beb-4819111bef9a&pf_rd_r=B45M076ESYPA6KCZ4QWG

iReadWrite itunes.apple.com/us/app/ireadwrite/id600843386?mt=8

Our Favorite Apps gatfl.org/favorite-search.php

Pediatric Treadmills carlinscreations.com

TRANSITION

Checklist for the first 21 years (PDF) ssdmo.org/assets/123/step3/checklist_for_first_21.pdf

Department of Elementary and Secondary Education

dese.mo.gov/se/ep/transition_resources.htm

Explore your future: Tools for

students https://www.ssdmo.org/rotate_features/11_13/transition_resources.html

Planning for Adult Life ssdmo.org/step3.html

SSD Transition Guidebook (PDF)

ssdmo.org/assets/123/step3/guidebook.pdf

Transition Coalition transitioncoalition.org/transition/section.php?pageId=150

VOCATION / VOLUNTEERING

America's Career InfoNet acinet.org/acinet

DESE Vocational Rehab (Adults) dese.mo.gov/vr/vocrehab.htm

Easter Seals Midwest <https://www.easterseals.com/our-programs/employment-training/>

Employment https://www.ssdmo.org/step3/Supports_for_Employment.html

Mers Goodwill <https://mersgoodwill.org/programs-services/>

St. Louis Arc slarc.org/site/446/employment_services.aspx

Work Support worksupport.com

HOUSING / INDEPENDENT LIVING

National Council on Independent Living <https://ncil.org/>

St. Louis Arc slarc.org/site/464/residential_services.aspx

St. Louis Life stlouislife.org

SELF DETERMINATION / SELF-ADVOCACY

Arc's Self-Determination Scale (PDF) <https://www.milestones.org/files/legacy/2012/02/the-arc-self-determination-scale.pdf>

Learn more about promoting self-determination in the home (PDF) <https://beach.ku.edu/sites/default/files/inline-files/Ten%20Steps%20to%20Independence%20-%20Promoting%20Self-Determination%20at%20Home.pdf>

National Resource Center Fact Sheet: Summary of Self-Determination (PDF) <https://thechp.syr.edu/wp-content/uploads/2013/10/determination.pdf>

RECREATION / LEISURE

Camp Barnabas campbarnabas.org

Challenger Baseball challengerbaseball.org

Kids Enjoy Exercise Now (KEEN) keenusa.org

PALS Program palsprogram.org

Recreation Council of Greater St. Louis recreationcouncil.org

Special Olympics specialolympics.org

STAGES Performing Arts Academy Access the Arts stagesstlouis.org

Sunnyhill Adventures sunnyhilladventures.org

Team Activities for Special Kids tasksports.org

Turner Center for the Arts turnercenterforthearts.org

Wonderland Camp wonderlandcamp.org

LEGAL / FINANCIAL

American's with Disabilities Act ada.gov

HUD.gov: Disability rights

https://www.hud.gov/program_offices/fair_housing_equal_opp/disability_main

Legal Service of Eastern Missouri lsem.org

Missouri Family to Family Resource Center

<http://mofamilytofamily.org/>

Midwest Special Needs Trust www.midwestspecialneedstrust.org

NBC Capital Impact ncbcapitalimpact.org

National Disability Institute <https://www.nationaldisabilityinstitute.org/>

National Organization on Disability nod.org