

## SPINA BIFIDA RESOURCES

Below are national and local resources for individuals with special healthcare needs and spina bifida.

### Adapted Sports/Camps/ Recreation

#### Adapted Sports

##### National

*National Center on Health, Physical Activity and Disability*

<http://www.ncpad.org/>

Newsletter and resources

*Disabled Sports USA*

<http://www.dsusa.org/>

State chapters are listing with sports programs.

*Special Olympics*

[www.specialolympics.org](http://www.specialolympics.org)

Provides sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities

*U.S. Paralympics*

[www.usparalympics.org](http://www.usparalympics.org)

Provides sports training for U.S. paralympic athletes

##### District of Columbia

*Blaze Sports Washington DC*

Free sports programs for children and adults with physical disabilities offered through the National Rehabilitation Hospital. Programs include: wheelchair basketball and tennis, power soccer, quad rugby, sled hockey, sit volleyball.

Contact: Joan Joyce, CTRS 202-877-1420 [joan.p.joyce@medstar.net](mailto:joan.p.joyce@medstar.net)

##### Maryland

*Baltimore Adapted Recreation and Sports (BARS)*

A community based non-profit organization dedicated to providing year round recreational opportunities to children and adults with disabilities. Advanced registration is required for all programs. 410-771-4606 [www.barsinfo.org](http://www.barsinfo.org)

*Bennett Institute Physically Challenged Sports Program*

Kennedy Krieger Institute, 3835 Greenspring Avenue, Baltimore, MD 21211

Contact: Gerry or Gwena Herman 443-923-7844 [hermang@kennedykrieger.org](mailto:hermang@kennedykrieger.org)

Programs: archery, wheelchair basketball, football, softball, fitness and swimming, wheelchair floor hockey, skiing, ice skating.  
Registration/Fees

##### Virginia

*Fairfax Falcons Wheelchair Sports*

[www.fairfaxfalcons.org](http://www.fairfaxfalcons.org)

Wheelchair basketball on Saturdays

#### Camps

##### National

[www.MySummerCamps.com](http://www.MySummerCamps.com)

Website provides links to disability-specific summer camps nationwide.

[www.CampResource.com](http://www.CampResource.com)

Website lists 72 special needs camps nationwide.

## Local

### *Camp Greentop*

15001 Park Central Road  
Sabillaville, MD 21780  
301-416-0801

[www.campgreentop.org](http://www.campgreentop.org)

Resident and respite camp. Ages: 7+; Fee

### *Camp Spifida*

196 Rose Lane  
Port Trevorton, PA 17864  
570-374-4907

[www.campspifida.org](http://www.campspifida.org)

Resident camp for children with spina bifida Ages:6-18; Fee

### *Camp Variety for Spina Bifida*

The Woodlands/Spina Bifida Association of Western Pennsylvania  
134 Shenot Road  
Wexford, PA 15090  
724-935-5470

Summer camping program for ages 6-young adults: swimming, adaptive sports, cooking, career exploration, art.

### *Easter Seals Camp Fairlee Manor*

22242 Bay Shore Road, Chestertown, MD 21620  
410-778-0566

Resident and respite camp, Ages: 6+; Fee

### *Victory Junction*

4500 Adam's Way  
Randleman, NC 27317  
336-498-9055

[www.victoryjunction.org](http://www.victoryjunction.org)

Resident camp for children with special health care needs. Ages: 6-16; Free

## **Recreation**

### *Chesapeake Region Accessible Boating*

Sandy Point State Park  
Annapolis, MD 21401  
410-626-0273

Provides sailing opportunities for individuals with disabilities

### *DC Department of Parks and Recreation*

*Therapeutic Recreation Services Branch*  
202-645-3995

### *Maryland Recreation and Parks Association*

301-942-7203

Contact for listings of local recreational activities.

### *Maryland Therapeutic Riding*

Annapolis, MD  
410-267-8900

[www.HorsesThatHeal.org](http://www.HorsesThatHeal.org)

Provides year-round therapeutic riding sessions; Fee

*The League for People with Disabilities Hobbs Fitness Center*

111 East Cold Spring Lane, Baltimore, MD 21239

410.323.0500

Fully accessible exercise center and swimming pool; individualized exercise programs, physical and aquatic therapy; Membership fee

*Therapeutic Recreation Programs-* Contact county recreation departments for therapeutic recreation programs

*Therapeutic and Recreational Riding Center*

Glenwood, MD

410-489-5100

Specialized riding program for individuals with special needs; Fee

*Wish-A-Fish Foundation*

410-551-5024

[www.wish-a-fish.org](http://www.wish-a-fish.org)

Provides families with children with special needs an opportunity to spend a day on the water fishing

## **Associations**

### **National**

*Hydrocephalus Association*

4340 East West Highway, Ste. 905

Bethesda, MD 20814

888-598-3789

[www.hydroassoc.org](http://www.hydroassoc.org)

Services: conferences, blog, online resource library

*Spina Bifida Association*

1600 Wilson Blvd., Ste. 800

Arlington, VA 22209

800-621-3141

[www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)

Services: publications, education programs

### **Local**

*Spina Bifida Association of Maryland*

<http://www.sbmaryland.com/contact.html>

410-665-1543

Programs and services- support group, education and social programs, financial assistance

Service area: Baltimore City, Anne Arundel, Baltimore, Carroll, Frederick, Harford and Howard Counties

*Spina Bifida Association of the National Capital Area*

<http://www.sbanca.org>

703-455-4900

Programs and services- monthly support groups, member directory, social activities, loan closet

Service area: Metro Washington area

## **Disability-Related Support Services**

### **National**

*Administration on Developmental Disabilities*

<http://www.acf.hhs.gov/programs/add/>

*Rehabilitation Services Administration-Office of Special Education and Rehabilitation Services (OSERS) - U.S. Dept of Education*

<http://www.ed.gov/about/offices/list/osers/rsa/index.html>

Local

*Developmental Disabilities Administration*

[www.ddmaryland.org](http://www.ddmaryland.org)

410-767-5600

Services: *Individual Family Services*-provide support services (other than residential and day habilitation) for adults living with their families or on their own; respite services, transportation, environmental modifications, adaptive equipment, money management, and home skills. *Family Support Services*- services are designed to help families stay together and are flexible and responsive to what the family needs, when they need it. Ages: under 22 with developmental disabilities living at home

*Maryland Department of Developmental Disabilities*

[www.mdod.maryland.gov](http://www.mdod.maryland.gov)

410-767-3660

Services: attendant care program, constituent services program, employed individuals with disabilities program, technology assistance program, workability loan program for individuals in Maryland.

Attendant Care Program – 800-637-4113: Offers financial reimbursement to eligible individuals with chronic or severe physical disabilities who require attendant services. The program allows consumers to supplement the cost of attendant care through a stipend.

Constituent Services Program- 800-637-4113: Provides information and referral, resource listings and access assistance to individuals with disabilities on: employment, housing, transportation, education, and benefits.

Employed Individuals with Disabilities Program- 800-637-4113: Program extends Medical Assistance health benefits to working Marylanders with disabilities

Technology Assistance Program (MDTAP) – 800-832-4827: Services: assistive technology loan program, training workshops on the use of assistive technology, an equipment loan program, directories of vendors and providers for home modification, durable medical equipment and assistive technology.

WorkAbility Loan Program: 800-832-4827: Program helps Maryland residents with disabilities qualify for low interest loans to buy equipment to be able to telework or start small businesses.

*Maryland Department of Human Resources*

[www.dhr.state.md.us](http://www.dhr.state.md.us)

800-332-6347

Services: adult protective services, adult and elderly services, burial assistance, child protective services, child support, energy assistance, in-home aides, independent living, purchase of care. Services are administered through local departments of social services.

*Division of Rehabilitation (DORS)*

[www.dors.state.md.us](http://www.dors.state.md.us)

410-554-9385

Services: Independent living, client assistance and transitioning.

Another Path: Independent Living Program- Provides support services at home and in the community for individuals with disabilities who are unable to be employed. Services can last from a few months to several years.

Disability Determination Services – 410-308-4500: Federally funded program administered with the Social Security Administration for individuals who are unable to work because of their disabilities. The DDS program develops the medical, functional and vocational documentation necessary to qualify individuals with disabilities for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

Workforce and Technology- 888-200-7117: Provides comprehensive vocational rehabilitation services.

Supported Employment Program- Provides and arranges for time limited supported employment for persons with severe disabilities who are not eligible for other DORS services.

Vocational Rehabilitation Program- Vocational counseling, medical and psychiatric treatment, rehabilitation technology, job training, job placement and support services.

*The ARC of Baltimore*

410-296-7667

Services: adult day services, information/referral, individual and family counseling, psychological services, respite care.

## Education

### National

[www.disabilityfriendlycolleges.com](http://www.disabilityfriendlycolleges.com)

Website has a guide to 75 disability friendly colleges and their services and blog.

*Office of Special Education Programs-U.S. Dept of Education*

<http://www2.ed.gov/about/offices/list/osers/osep/index.html>

### Local

*Maryland State Department of Education*

410-767-0100

[www.marylandpublicschools.org](http://www.marylandpublicschools.org)

*Career Technology and Adult Learning-* 410-767-0536: Administers and monitors federally funded career and technology programs in high schools and community colleges. Serves: Developmentally disabled students ages 14-26 years old.

*Equity Resource Center-* 301-405-2083 Services: Advocacy and career development for individuals with developmental disabilities. Online resource directory includes videos and books on career development.

*Division of Special Education* – 410-767-0238

Provides coordination of family support services through the *Infant and Toddlers Program* and *Partners for Success*

*Infant and Toddlers Program-* 410-767-0261 Services: Infants and children up to age 3 can receive audiology testing, physical therapy, health services, nutrition services, occupational therapy, speech-language, transportation, service coordination, assistive technology, family training and home visits. Contact local health department for services by county.

*Partners for Success: Resource Centers for Families and Schools-* 410-767-0267 Resources: resources, referral, training and support for families with children with disabilities. Centers are located in each county. Contact local Board of Education.

*Other Special Education Services-* Preschool services for children under age 4 are available by jurisdiction and by needs of child.

Transportation and accommodations are services available to age 21.

## Financial Assistance

### National

*Aubrey Rose Foundation*

3862 Race Road

Cincinnati, OH 45211

513-265-5801

[www.aubreyrose.org](http://www.aubreyrose.org)

Provides grants to individuals with life-threatening condition for uncovered medical expenses. Go to website to apply for grant.

[www.benefits.gov](http://www.benefits.gov)

Online access to government benefit and assistance programs

*United Healthcare Children's Foundation*

<http://www.uhccf.org/>

The Foundation provides financial assistance to families of children whose commercial insurance coverage does not fully cover the cost of treatment.

### Local

*Maggie's Light Foundation, Inc.*

410-335-2760

[www.maggieslight.org](http://www.maggieslight.org)

Services: Provides financial assistance for respite, camp, recreation for children and young adults with special health care needs, identify caregivers, local/state resources, newsletter.

*Low Intensity Support Services*

Financial assistance program of the Developmental Disabilities Administration, the program provides funding up to \$3,000 per person per year for individual and family counseling, personal and attendant care, day care, specialized equipment, health services, respite care, housing adaptations, and therapeutic services. These funds are available on first-come, first serve basis for eligible people.

For *LISS Request Form* and provider list, visit: <http://dda.dhmd.maryland.gov/SitePages/liss.aspx>

*Spina Bifida Association of Maryland*

<http://www.sbmaryland.com/contact.html>

410-665-1543

Provides financial assistance through brace and camp funds for members

Service area: Baltimore City, Anne Arundel, Baltimore, Carroll, Frederick, Harford and Howard Counties

*The Coordinating Center*

8531 Veterans Highway, 3<sup>rd</sup> Floor

Millersville, MD 21108

410-987-1048

Services: *Take a Break* respite program. Anne Arundel County only

## **Health Care**

National

*Medicaid and Medicare*

[www.cms.gov](http://www.cms.gov)

Information about Medicaid and Medicare from the Centers for Medicare and Medicaid services

*Needy Meds*

[www.needymeds.org](http://www.needymeds.org)

Information on medication assistance programs, disease-based assistance, free or low-cost clinics, government programs and other types of assistance programs that help with costs related to health care.

*Partnership for Prescription Assistance Programs*

[www.pparax.org](http://www.pparax.org)

Helps qualifying patients without prescription drug coverage get medicines they need for low-cost or free.

*Patient Assistance Program*

401-729-3284

[www.rxassist.org](http://www.rxassist.org)

Services: locator for pharmaceutical companies and medications manufactured to provide free medications.

*The Catalyst Center*

[www.catalystctr.org](http://www.catalystctr.org)

Services: a national center dedicated to improving healthcare coverage and financing for children and youth with special healthcare needs.

*The Patient Advocate Foundation*

[www.patientadvocate.org](http://www.patientadvocate.org) Services: helps patients who cannot afford their insurance co-pays.

Local

*Fehsenfeld Center*

410-323-0500

Services: Licensed medical day care program for adults with acquired brain injuries and various neurological impairments.

*Kennedy Krieger Institute*

707 North Broadway

Baltimore, MD 21205

800-873-3377

Comprehensive outpatient and inpatient treatment for individuals with developmental disabilities

*Keilty Center for Spina Bifida and Related Conditions* – 443-923-9400

*Kennedy Krieger Child and Family Support Program*

888-554-2080

Services: Provides home-based treatment, parent training and counseling by team of occupational, physical, speech therapists and social workers.

*Maryland Health Partners*

1-800-888-1965

Services: list of mental health core service agencies in each county.

*Maryland Pharmacy Assistance Program*- 800-226-2142: Helps eligible Maryland residents pay for medically necessary prescriptions.

*Maryland State Department of Health and Mental Hygiene*

Children's Medical Services Program – 410-767-5745: Provides medical services to children with special health care needs up to 200% of the federal poverty level. Ages: birth to 22 are covered; Contact local health department.

*Mt. Washington Pediatric Hospital*

1708 Rodgers Avenue

Baltimore, MD 21209

800-999-9442

Provides home-based, short-term nursing care and rehabilitative services to children with chronic illnesses and physical disabilities; physical, occupational, speech therapy. Provides short-term hospitalization for physically disabled children for purpose of family respite

*PACT*

7000 Tudsbury Road

Gwynn Oak, MD 21244

410-783-9461

Within My World; Program provides medically based child care services for children six-weeks to five years; full-day child care, nursing services, early intervention services, social work support.

### **Independent Living, Housing, Employment**

#### National

*U.S. Department of Education-Centers for Independent Living*

<http://www.ed.gov/programs/cil/index.html>

*U.S. Department of Labor Disability Resources & Office of Disability Employment Policy (ODEP)*

<http://www.dol.gov/dol/topic/disability/index.htm>

*Social Security Disability Benefits*

<http://www.ssa.gov/pgm/disability.htm>

Programs: The Social Security Administrations provide benefits through two programs- the *Social Security Disability Program* and *Supplemental Security Income (SSI)*. Visit website for information regarding eligibility, how to apply and how to appeal a claim denial.

#### Local

*Abilities Network*

410-282-5900

[www.abilitiesnetwork.org](http://www.abilitiesnetwork.org)

Services: *Community Partners*- program helps with independent living skills to support individuals in their own homes.

*By Their Side*

443-279-1234

[www.bytheirsideside.org](http://www.bytheirsideside.org)

Services: Personal Advocate services for individuals with intellectual/developmental disabilities. Membership application fee: \$2400 initial fee; \$50 annual fee; \$79/hr. advocate fee

*Maryland Department of Housing and Community Development*

800-756-0119

The Department provides housing resources for individuals with disabilities.

Homeownership for Individuals with Disabilities/Single Family Housing – 410-514-7535

Maryland Department of Human Resources

[www.dhr.state.md.us](http://www.dhr.state.md.us)

800-332-6347

Services: *Housing Counselor Program*- assists low income families who are homeless or in imminent danger of becoming homeless to locate, secure and maintain permanent housing; *Homelessness Prevention Program/Eviction Prevention*- provides non-monetary assistance to households with a pending eviction; *Rental Allowance Program*- monthly rental assistance to low income households who are homeless or have an emergency housing need.

*Social Security Administration*

6401 Security Blvd.

Baltimore, MD 21235

800-772-1213

Provides information on SSDI, SSI and Medicare

### **Information and Referral Services**

National

*2-1-1 Information and Referral Call Centers*

<http://www.211.org/>

Free information and referral lines for health, human and community services. 2-1-1 provides information on emergency food pantries, rental assistance, public health clinics, child care resources, support groups, legal aid.

*CDC – Spina Bifida* [www.cdc.gov/ncbddd/spinabifida](http://www.cdc.gov/ncbddd/spinabifida)

Children with Spina Bifida – A Resource Page for Parents & Professionals [www.waisman.wisc.edu/~rowley/sb/kids/](http://www.waisman.wisc.edu/~rowley/sb/kids/)

*Disability Information* [www.disabilityinfo.gov](http://www.disabilityinfo.gov)

National Center for Learning Disabilities [www.ncl.org](http://www.ncl.org)

National Information Center for Children and Youth with Disabilities <http://nichcy.org>

Local

*Caring Communities*

<http://caringcommunities.org>

Resources: large regional expo for disability services; respite care registry

*First Call for Help*

410-685-0525

24 hours/7 days week information and referral service for health and human service needs

*Kennedy Krieger Institute Resource Finder*

800-390-3372

<http://resourcefinder.kennedykrieger.org/>

[resourcefinder@kennedykrieger.org](mailto:resourcefinder@kennedykrieger.org)

Resources: Information and support for individuals with developmental disabilities and families

*Maryland Children and Youth with Special Health Care Needs Resource Locator*

<http://specialneeds.dhmf.maryland.gov>

Resources: Over 800 resources user friendly and accessible in over 50 languages: child care/respite care, community support services, education, family support services, financial assistance, government agencies, home care services, medical/dental services, mental/behavioral health care, therapeutic services, transportation, youth transition.

*Maryland Coalition of Families for Children’s Mental Health*

800-607-3637

[www.mdcoalition.org](http://www.mdcoalition.org)

Resources: information and support provided by family navigators available in each county; education programs.



*Parents' Place of Maryland*

410-859-5300

[www.ppmmd.org](http://www.ppmmd.org)

Statewide resource center for families of children with disabilities

Resources: workshops, parent-to-parent support, assistance with school issues.

*Sibshops*

410-578-5169

[sibshopsofmaryland@yahoo.com](mailto:sibshopsofmaryland@yahoo.com)

Programs: Saturday social activities for kids ages 8-13 who have a sibling with special needs. Serves: Baltimore, Montgomery, Harford and Howard Counties

*Transitioning Youth*

[www.mdtransition.org](http://www.mdtransition.org)

Website for families and youth with disabilities

Resources: transition planning, post secondary education, healthcare, transportation, and support services.

### **Legal Services**

Local

*Maryland Center for Inclusive Education*

410-859-5400

[www.mcie.org](http://www.mcie.org)

Services: provides free legal services to students with disabilities seeking inclusion in their community schools, resources and education programs.

*Maryland Disability Law Center*

800-233-7201

Services: Provides free legal services to clients receiving inpatient psychiatric care, entitlement to government benefits or special education services.

*Project Heal*

443-923-4416

A partnership between Kennedy Krieger Institute and the Maryland Volunteer Lawyers Service

Services: Provides free legal and advocacy services to low-income children with developmental disabilities.

*The Coordinating Center*

8531 Veterans Highway, 3<sup>rd</sup> Floor

Millersville, MD 21108

410-987-1048

Services: Provides medical legal services and litigation support.

### **Publications**

*Ability Magazine*

[www.abilitymagazine.com](http://www.abilitymagazine.com)

A leading magazine that focuses on health, disability and human potential and provides new insights on individual levels of ability

*Exceptional Parent*

[www.eparent.com](http://www.eparent.com)

Online magazine for parents of children and young adults with disabilities, includes news forum, inks, and online bookstore.

*New Mobility*

[www.newmobility.com](http://www.newmobility.com)

An online magazine for users of wheelchairs

## Transportation

### Local

*Maryland Transit Administration*

800-543-9809

Services: Provides regional bus and rapid transit services in the Baltimore metro area.

Call-A-Lift- Call 410-682-5438 by 4:00 p.m. the day before transportation is needed. Provides lift-equipped busses on any route that does not have pre-scheduled accessible buses

Metro/Light Rail Service- Fully accessible

Mobility- 410-727-3535: Provides curb-to-curb transportation in Baltimore City, Anne Arundel and Baltimore counties to disabled persons who cannot use regular public transportation. Must have physician-certified disability; Application required. Small fee

Reduced Fare Program for People with Disabilities-410-767-3441 (certification office) Application, including a signed statement from a health professional is required to receive a MTA photo ID card that entitles cardholder to reduced fares.

*Compiled by: Chesapeake-Potomac Spina Bifida, Inc., January 2017*

