**Timeline of Services for Children and Adults with Spina Bifida**

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<th>Birth-3 years old</th>
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<td><strong>BENEFITS AND INSURANCE</strong></td>
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<td><strong>EDUCATION AND EMPLOYMENT SERVICES</strong></td>
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<td>Early Intervention</td>
<td>Pre School Transition</td>
<td>School Age Education Services (IEP/504)</td>
<td>IEP Transition Planning</td>
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<td><strong>SOCIAL SUPPORTS AND LEISURE</strong></td>
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<td><strong>HEALTHCARE PLAN</strong></td>
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<td>Primary Care Doctor/ Other Specialists &amp; Dentist/ Women’s Health Doctor</td>
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Resources for Children and Adults with Spina Bifida

Benefits and Insurance

Medicaid/All Kids
800.843.6154
dhs.state.il.us
A program of medical aid designed for those unable to afford traditional medical services. Medicaid/All Kids is administered by the Illinois Department of Human Services, and it is financed by state and local governments.

Division of Specialized Care for Children (DSCC)
1.800.322.3722
https://dscc.uic.edu/
DSCC’s mission focuses on public service, education, and the coordination of family-centered care for eligible children with special health care needs in Illinois for children from birth to 21 years of age. DSCC may be able to provide additional help to pay for specialty care for certain medical conditions and equipment.

Supplemental Security Income (SSI) Title XVI
800.772.1213
ssa.gov
Supplemental Security Income, also known as SSI, provides monthly payments to people 65 or older, or individuals who are blind or disabled. The office will look at both disability and financial situation. Children and adults can apply for SSI, and once a person is 18 years old, parent’s income is no longer considered when evaluating financial status.

Social Security Disability Insurance (SSDI) Title II
800.772.1213
ssa.gov
SSDI pays benefits to you and certain members of your family if you are “insured,” meaning that you worked long enough and paid Social Security taxes. Your children over the age of 18 who have a disability may receive benefits if you worked long enough and paid Social Security taxes and you are retired, disabled or deceased. These adult children are termed “disabled adult child” (DAC).

WIC
800.323.4769
http://www.dhs.state.il.us/page.aspx?item=30513
WIC is a supplemental nutrition program for women, infants, and children. WIC may help to provide healthy food (or certain types of formulas) if mom is pregnant or breastfeeding, has a child under 5 years old, has limited income, and is looking to improve the family’s health and nutrition education.
Division of Developmental Disability (DDD)
800.843.6154
http://www.dhs.state.il.us/page.aspx?item=29761

Provides services and supports for individuals with developmental disabilities and their families. Possible services include: in-home supports, respite care, training programs, job coaches, residential living arrangements, adaptive equipment, and other supports. Coordination agencies are located throughout Illinois. Intake Coordinators will complete a "Prioritization of Urgency of Need for Services" (PUNS) form.

Respite Services
1.888.DD.PLANS
https://dssc.uic.edu/how-we-help/our-programs/home-care-program/
Short-term, temporary care provided to an individual in their home or outside their home. Respite is designed to give the primary caregiver(s) a break from their care giving duties. Respite may be just a few hours or several days in length, depending on the plans of the caregiver. Respite may be planned in advance or may be made available to assist in a crisis/emergency situation.

Education and Employment Services

Early Intervention
217.782.1981
http://www.dhs.state.il.us/page.aspx?item=30321

Illinois’ Early Intervention program’s mission is to assure that infants and toddlers, birth to three, with diagnosed disabilities, developmental delays, or risk of significant delays receive resources and supports that assist them in maximizing their development. Some services may include occupational and physical therapy and social work support. Early Intervention coordinators can also help children transition into pre-school.

Individualized Education Program (IEP)
Illinois State Board of Education
https://www.isbe.net/Pages/Special-Education-Individualized-Education-Program.aspx

Children with delayed skills or other disabilities might be eligible for special services that provide individualized education programs in public schools, free of charge to families. Understanding how to access these services can help parents be effective advocates for their children. Parents can work with educators to develop a plan — the individualized education program (IEP) — to help children succeed in school. The IEP describes the goals the team sets for a child during the school year, as well as any special support needed to help achieve them. At age 14, the IEP will start to address transition planning and preparing for the future. By age 17, all teens should start to have a post high school plan. With an IEP, certain students may be eligible to continue until their 22nd birthday.
Vocation Rehabilitation- Division of Rehabilitation Services (DRS)
http://www.dhs.state.il.us/page.aspx?item=29764
The Division of Rehabilitation Services is Illinois’ lead agency serving individuals with disabilities. DRS works in partnership with people with disabilities and their families to assist them in making informed choices to achieve full community participation through employment, education, and independent living opportunities.

Work Incentive Planning
800.807.6862
https://www.ssa.gov/work/WIPA.html
For people receiving Supplemental Security Income (SSI) who want to work, it is important to meet with a work incentive coordinator and understand how SSI benefits may be affected by employment.

ICRE- Illinois Center for Rehabilitation Education
http://icre-roosevelt.org/
The Illinois Center for Rehabilitation and Education – Roosevelt (ICRE-R) is a residential school for students with severe physical disabilities. ICRE-R offers a two year comprehensive Transition Program that provides young people with physical disabilities, ages 18-22, instruction and opportunities to make a successful transition to adult life.

Alternative College Experience Programs/ Comprehensive Transition Programs
https://thinkcollege.net/about/what-is-think-college
Many universities across the country are developing programs that are specifically designed to provide individuals with intellectual or developmental disabilities (who may not thrive in traditional college classes) a traditional college experience- complete with dorm rooms, cafeterias, and job training. Access programs focus on academics, campus life, community involvement, employment opportunities, socialization, and self-awareness. Many programs allow students to audit classes without gaining credit, take classes for credit, or even transition into a degree seeking program if they choose to at a later date. Most programs offer a certificate of completion and provide students with many new life experiences. These programs are considered a Comprehensive Transition Program, so students are eligible for financial aid.

Traditional College Programs
https://ablethrive.com/activities/21-colleges-adapted-sports-programs (even if sports are not a goal, these schools offer physically accessible campuses and significant disability support services)
https://tinyurl.com/accomidationdifferencescollege (differences between high school and college)
Most universities have an Office of Disability Services that is specifically designed to support students with disabilities during their college experience. In addition to touring schools and determining if you can see yourself on campus, it is also important to meet with Disability Services and discuss what supports are available to students. Some universities offer adaptive sports, supportive living environments, accessible buses on campus, or other resources that are designed to make life easier. It is important to evaluate colleges based upon a student’s physical and educational needs. Ask questions to assure that you understand how accommodations differ from high school to college. College will not provide the same levels of support available in an IEP.
**Illinois- Transition Services for Youth with Disabilities Secondary Transitional Experience Program**

http://www.dhs.state.il.us/page.aspx?item=35174

STEP is a work experience program that helps students with disabilities prepare to transition to employment and community participation during and after high school.

**Social Supports**

**Illinois Spina Bifida Association of Illinois (ISBA)**
773.444.0305
https://www.isba.org/

The Illinois Spina Bifida Association works to improve the quality of life of children, adults, and families living with spina bifida. ISBA works to accomplish its mission with a three-part program strategy: Promote skills development and independence; Improve family resilience and access to resources through outreach, education and advocacy; and Provide targeted financial assistance. ISBA programs include: Community-Clinic Connection, Camp Independence (run by the YMCA of Metro Chicago, in association with ISBA), GoBabyGo events, ABLE Savers, Conferences, Clinic Outreach, Information & Referral, Statewide Support Groups, Play Dates, Adult Groups, Holiday Parties, Post-High School Scholarships, Equipment Fund, and Research Awards.

**ParentWISE and PeerWISE**
312.227.3280
https://www.luriechildrens.org/en/patients-visitors/resources-support-services-for-families/parentwise/

Parent Wisdom In Shared Experience is a Lurie Children’s volunteer program that supports parents during their child’s diagnosis and treatment. ParentWISE volunteers are parents who know first-hand what it is like to care for a seriously ill child. Building on the common bond of their children’s illness or care experience, ParentWISE volunteers connect, empower and support parents. There are parents you can talk to who also have a child with spina bifida. PeerWISE partners patients with mentors with a similar medical diagnosis for support.

**Sibshop**

Advocate Illinois Masonic Pediatric Developmental Center Sibshop
3040 N. Wilton, 2nd Floor, Chicago, IL 60657
(Many different cities and states offer Sibshops, too)
773.296.8127
siblingsupport.org

Sibshop Groups are for brothers and sisters of a person with special needs. Sibshops include a mix of new games (designed to be unique, off-beat and appealing to a wide ability range), new friends and discussion activities. The goal of Sibshop is to provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting, share joys and concerns over their siblings, and learn how others handle situations commonly experienced by siblings of children with special needs.
Illinois Network of Centers for Independent Living
http://www.incil.org/
A non-residential, community based organization, directed and managed by persons with disabilities, which is dedicated to the philosophy that all people with disabilities have the right and the responsibility to make choices to control the direction of their lives and participate fully and equally in their communities. Many centers provide life skills training, peer support and various resources.

SAILS: Supporting Adolescents with Independent Life Skills
312-227-6391
SAILS is a 6 week program for teens 14-20 to teach teens to prepare for their future in work, college and managing their health care and a fun place to meet other teens. There is also sessions for parents to provide additional information and support. Call the Transition Team to see when the next sessions are available.

Access Living’s Group for Young Women
https://www.accessliving.org/180
The Empowered Fe Fes is a young women’s advocacy and peer support group that is committed to creating change in the lives of young women with disabilities. Members will get the chance to meet other young women with disabilities and build campaigns around disability and women’s rights. Our meetings also allow time for the group to have discussions about disability pride, gender inequality, self-care, dating and relationships, self-advocacy and other topics.

Access Living’s Independent Living Skills Training Program
https://www.accessliving.org/Reaching-Our-Dreams
Reaching Our Dreams was developed as a way to help youth develop skills that will enable them to become independent and more invested in planning for their futures. The program teaches: time and money management, dealing with parents, communication skills and hygiene.

Access Living’s Roll Models Program for Girls and Women with Disabilities
https://www.accessliving.org/138JK86
M&M “Roll” Model Program fosters new and ongoing mentoring relationships between teen girls with disabilities (13—19 years old) and women with disabilities. Mentees and Mentors have various disabilities and come from diverse cultural socio-economic backgrounds.

Access Living’s Disability Justice Mentoring Collective
https://www.accessliving.org/Disability-Justice-Mentoring-Collective
DJMC provides a unique opportunity for youth with disabilities, ages 12 to 24, to receive guidance and support from a mentor who cares about disability justice. Disability justice is beyond disability rights—being sure that people have access to society and full inclusion beyond what is the law. In particular disability justice is about furthering the power of people of color with disabilities.
Adaptive Equipment Resources & Grants

**Lekotek**  
http://www.lekotek.org/  
Lekotek improves the lives of children with disabilities through toys and play. Lekotek offers therapeutic play-based family sessions for families of children with disabilities. Sessions are structured to help children learn, develop and thrive in a world that presents them with many unique and complex challenges.

**Community Ramp Builders Program**  
http://www.ramps.org/free-ramps.htm  
A resource for families seeking no-cost home entry ramps.

**United Healthcare Children’s Foundation**  
https://www.uhccf.org/apply-for-a-grant/  
UHCCF’s mission is to help fill the gap between what medical services/items a child needs and what their commercial health benefit plan will pay for. UHCCF grants provide financial help/assistance for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan.

**Variety Children’s Charity**  
http://varietyofillinois.org/  
Variety’s Kids on the Go program provides mobility equipment not covered by insurance for children with disabilities, and the Live to Achieve program encourages participation & excellence in adaptive sports.

**Cameron Can Foundation**  
http://www.cameron-can.com/  
Cameron Can Foundation recognizes that caring for a child with a disability can be expensive. Many families make too much money to qualify for state aide, but too little money to thrive. The foundation offers stipends for families who do not qualify for Charity Care, DSCC, Medicaid and other financial assistance programs. The stipends may be used for a wide variety of supports and programs to assist their family member with special needs. Some examples of past uses: Hippotherapy (Therapeutic horseback riding), Paying down outstanding hospital balances, Therapies (Physical, Occupational, Speech, Developmental), Special Recreation Camps, Education Advocacy

Sport and Recreation Opportunities

Recreation and sports are important for all kids, and especially people with spina bifida who may be at greater risk for obesity. We recommend that everyone participate in some type of structured recreational program at least one time per week. This may include sports, church, volunteer, after school clubs, boy scouts, and many more.

**Disabled Sports USA, Local Chapters- Dare2tri, Great Lakes Adaptive Sports Association, and SRA Lab Sports & Fitness**  
https://www.disabledsportsusa.org/location-map/  
Local organizations Dare2tri, SRA Lab- Sports & Fitness, and Great Lakes Adaptive Sports Association offer sport and recreation programming for youth and adults who have a primary physical disability.
Caring for Kids Recreation Program at SRA Lab
https://www.sralab.org/services/caring-kids-program
Caring for Kids provides kids from ages 7 to 17 with an opportunity to try a wide range of year-round adaptive sports, social, arts, cultural and camp programs.

Special Recreation Associations of Illinois
http://www.specialrecreation.org/
Special Recreation Associations assure that local park districts and village recreation programs are inclusive of individuals with disabilities. Special recreation programs offer physical activity programs, aquatics, crafts, and social events. Some special recreation programs offer adaptive sports that specifically serve those with physical disabilities. There are currently 33 Special Recreation Associations across the state of Illinois.

Camp Independence: YMCA
847.546.8086
https://www.ymcachicago.org/independence/
Camp Independence is a special place for campers age 7 and up with spina bifida and other neurological disabilities. The camp program is designed to build confidence, independence, make new friends and have fun. Located near Fox Lake in northern Illinois, Camp Independence offers one-week residential camp sessions in the summer and weekend retreats September through April. Campers benefit from a supportive and challenging environment that offers fun and educational experiences. Camp Independence’s mission is to provide programs that teach life skills, foster independence, build confidence, teach leadership and increase self-esteem.

Challenged Athletes Foundation
http://www.challengedathletes.org/
Challenged Athletes Foundation provides grants so individuals with disabilities can buy customized pieces of adaptive sports equipment, support training, and engage in sport specific travel.

Travel and Transit

Paratransit Services
http://www.pacebus.com/sub/paratransit/default.asp
Paratransit is a program for people whose disability may prevent them from using fixed route services for buses and "L" trains. Paratransit provides “door-to-door” transportation services for eligible people based on their disability. Participants are required to pay typical bus fare. You must call to set up an interview and apply for services (transportation can be provided to the interview).

Regional Transportation Authority Ride Free Permits and Reduced Fair Permits
1.800.624.2459
http://rtachicago.org/rider-resources/reduced-fare/ride-free-permits
The Illinois Department on Aging’s Circuit Breaker program provides grants to senior citizens and persons with disabilities to help them reduce the impact of taxes and prescription medications on their lives. Many individuals with spina bifida utilize the Ride Free Program, which offers free public transportation access to individuals who meet the disability and income requirements. You can apply online or call. Discounted ride programs are also available to those who do not meet income requirements.
Travel Training
http://www.rtachicago.org/rider-resources/accessible-transit/travel-training
The Regional Transportation Authority (RTA) Travel Training Program teaches individuals with disabilities how to use CTA, Metra, and Pace buses and trains.

Wheelchair Accessible Taxis & Ride Share
http://www.opentaxis.com/
773-657-3006 (phone), 773-609-5321 (text), Dispatch1@opendoorsnfp.org
Wheelchair accessible taxis are available through one centralized dispatch center, Open Taxi. Lyft and Uber also offer wheelchair accessible taxis through their ‘access’ option. ‘Access’ may need to be turned on in the settings menu of the app.

Taxi Access Program
The Taxi Access Program Allows ADA Paratransit eligible riders to take taxi rides (up to $20) for only $3. All Chicago taxis are required to accept TAP Cards.

Secretary of State- Disability Parking
http://www.cyberdriveillinois.com/services/persons_with_disabilities/disabilitiesfaq.html
Disability parking permits provide those with disabilities access to accessible parking spaces. The state of Illinois has recently revamped the meter exempt parking regulations. Many individuals with spina bifida meet the requirements for meter exempt (no-fee) parking, but new gray and yellow permits are needed to take advantage of this parking feature.

Driving with Hand Controls
https://www.sralab.org/lifecenter/resources/listing-driver-rehabilitation-programs-near-chicago
Individuals who lack leg strength and leg function can still drive a car, thanks to hand controls and other adaptive driving devices. Many centers around Chicagoland offer drivers evaluations and drivers training.

Future Needs Planning

Special Needs Trust
A Special Needs Trust is a specialized legal document designed to benefit an individual who has a disability. A Special Needs Trust enables a person under a physical or mental disability, or an individual with a chronic or acquired illness, to have, held in trust for his or her benefit, an unlimited amount of assets. In a properly-drafted Special Needs Trust, those assets are not considered countable assets for purposes of qualification for certain governmental benefits, such as SSI.

ABLE Accounts
https://savewithable.com/il/home.html
Individuals who receive SSI often have limits related to how much money they can save. ABLE accounts allow individuals with disabilities to save up to $100,000 without impacting SSI eligibility. Any investment earnings will be tax deferred or tax free (if used for qualifying disability related expenses).
Guardianship
http://www.cookcountyclerkofcourt.org/
Clerk of the Circuit Court – Cook
Daley Center, 12th Fl
Once a child turns 18 years of age they become their own guardian, and are legally responsible for their
own decisions. However, sometimes it can be difficult for a young adult to make all medical and financials
decisions on their own, and parents or doctors may have concerns about their ability to make decisions
independently. With guardianship, a parent or trusted relative or friend, helps make important decisions.
A guardian is given legal responsibility for the care of a disabled person. The disabled person must be 18
years of age or older, have mental/physical incapacity, mental illness or developmental disability and not
be fully able to manage person or estate. There are different levels of guardianship. Guardianship is filed
in your local circuit court. The $119 fee can be waived if you have a medical card.

Power of Attorney (Healthcare)
https://www2.illinois.gov/aging/ProtectionAdvocacy/Documents/POA_HealthCare.pdf
The purpose of Power of Attorney is to give the person you designate broad powers to make any and all
decisions concerning your personal care, medical treatment, hospitalization and healthcare and to
require, withhold or withdraw any type of medical treatment or procedure, even though your death may
ensue. The person you designate shall have the same access to your medical records that you have,
including the right to disclose the contents to others. The person you designate shall have full power to
make a disposition of any part or all of your body for medical purposes, authorize an autopsy and direct
the disposition
of your remains.

Adaptive Clothing

Adaptive Clothing by Target
https://www.target.com/c/adaptive-clothing/-/N-kzyrz
Target offers adaptive clothing for men, women, and children. Clothing is specifically designed to be
sensory friendly and to make dressing easier. Jeans are designed with minimal pockets to reduce
pressure points and a high rise waist to prevent pants from sagging while sitting in a wheelchair. Some
items offer snap or magnetic closures to allow for easier movement. Adaptive clothing looks and costs the
same as Target’s traditional clothing.

Tommy Hilfiger Adaptive
https://usa.tommy.com/en/tommy-adaptive
Tommy Hilfiger offers classic looks and design enhancements that make dressing easy. Velcro and
magnetic closures make button up shirts accessible to all. Side entry dresses and tear away jean legs
offer increased ease, all while being invisible and stylish. The adaptive line looks and costs the same as
Tommy Hilfiger’s traditional clothing.
Nike Flyease
Nike has designed stylish shoes that offer zipper and Velcro closures. Flyease shoes allow men, women, and children with limited hand dexterity the ability to dress more independently. Shoes are specifically designed to better accommodate braces and orthotics.

Zappos Adaptive
https://www.zappos.com/e/adaptive
Zappos offers a wide range of adaptive clothing and footwear. Styles and prices vary widely.

Little Royal Too
http://www.littleroyaltwo.com/
Calf length socks for babies younger than 24 months. A perfect fit for use with AFO’s. Colorful and $6 per pair!

Rock a Thigh Baby
https://www.rockathighbaby.com/
Thigh length socks for babies, youth, and teens. These colorful socks are great for under braces, and they range from $5-$10.

Billy Footwear
https://billyfootwear.com/
Billy footwear offers stylish shoes with zipper closures. The top of each shoe zips open and allows for easy entry/exit.

Smart Knit Socks
https://www.smartknit.com/
Smart Knit socks are seamless and specifically designed to be worn with braces and orthotics.

Shoe Goo - Shoe Repair
Shoe Goo allows you to easily repair and reinforce shoes. Goo is a good solution for individuals who drag their feet while walking or for those who wear the bottoms of their shoes unevenly. A low cost solution to extend the life of shoes.

Icon Underwear
https://www.iconundies.com/
Women’s cloth reusable underwear that is specifically designed to handle mild to moderate bladder leakage. Prices range from $30-$40 per pair. This company also makes Thinx ‘period-proof’ underwear.
Shoe Recommendations

Winter Boots for AFO’s- Any boot that laces up or is adjustable. Search “adjustable boot” on zappos.com or your favorite shoe retailer. Some options include Neo, Columbia Kids, Kamik Kids Rocket, Ugg Barley Adjustable, Tundra Quebec Kids Boots

Skater shoes with flat bottoms- Great for AFO’s. Some options include DC Kids Pure, Vans, See Kai, Tony Hawk High Tops, Plae Shoes, Airwalk Shoes,

Wide Shoes for AFO’s- Some brands include Asics, New Balance, Stride Rite, Keen, Tsukihoski

Shoes for Custom Inserts- Rigid sole shoes with deep heel cups, laces, removable liners, and an overall sturdy design. Some options include Asics, New Balance, Saucony, Brooks.

Healthcare

Primary Care Doctor
All children and adults should have a primary care doctor. Speak with your medical team if you need help connecting to a primary care doctor.

Shirley Ryan Ability Lab- Adult Spina Bifida Clinic
https://www.sralab.org/conditions/spina-bifida
The adult spina bifida clinic at SRA Lab is a multidisciplinary clinic with appointments on the first Friday morning of each month. Most patients from Lurie Children’s will transfer their spina bifida care to the adult clinic around 18-22 years of age. SRAL has various resources such as the assistive technology, orthotics, and vocational rehabilitation, which help individuals to lead more independent and fulfilling lives.

Please Note

**This list is not inclusive of all programs and some eligibility depends on your child’s medical condition, family income and other factors. Please speak with the spina bifida clinic social worker or resource specialist for more information or any questions regarding these potential resources.**