

# Agencies Listed on Timeline of Services 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 regular medical service and financed by the state and local governments. Medicaid/All Kids is administered by the Illinois Department of Human Services.

### Division of Specialized Care for Children (DSCC), Chicago Administrative Office

312.996.6380  
uic.edu/hsc/dsccl

DSCC's mission focuses on public service, education and research as a basis to provide, promote and coordinate family-centered, community-based, culturally competent 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 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 situation. Your local Social Security office can tell you more about your state's total SSI payment.

### 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  
dhs.state.il.us

WIC is a special supplemental nutrition program for women, infants and children. WIC may help 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. Call your local WIC clinic to schedule an appointment.



Artwork  
created by  
Hollis, age 12

## Education and Employment Services

### Early Intervention

217.782.1981  
dhs.state.il.us

Illinois' Early Intervention program's mission is to assure that families who have infants and toddlers, birth to three, with diagnosed disabilities, developmental delays or substantial risk of significant delays receive resources and supports that assist them in maximizing their child's development, while respecting the diversity of families and communities. Some services may include occupational and physical therapy and social work support. If your child is in Early Intervention, speak with your coordinator to start planning for the transition into pre-school once early intervention services end. To locate an agency in your area visit website.

### Individualized Education Program (IEP)

Illinois State Board of Education  
isbe.net

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 kids.

The passage of the updated version of the Individuals with Disabilities Education Act (IDEA 2004) made parents of children with special needs even more crucial members of their child's education team. Parents can now work with educators to develop a plan — the individualized education program (IEP) — to help kids 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

(See Rehab Life Skills: Division of Rehabilitation Services (DRS))

### Work Incentive Planning

800.807.6862  
dhs.state.il.us

For people receiving Supplemental Security Income (SSI) who want to work, they should meet with a community work incentive coordinator to understand how benefits may be affected by going or returning to work. Contact your local office to set up a free benefits planning session.

## Developmental Disability

### Division of Developmental Disability (DDD)

800.843.6154  
800.447.6404 (TTY)  
dhs.state.il.us

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.



Artwork  
created by  
Hollis, age 12

## Respite Services

1.888.DD.PLANS

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. There are many agencies throughout the Chicagoland area that provide this service. Contact your pre-admission screening (PAS) agent to find an agency in your area.

## Support and Leisure

### Spina Bifida Association of Illinois (SBAIL)

773.444.0305

sbail.org

The Spina Bifida Association of Illinois is a nonprofit organization dedicated to promoting prevention of spina bifida and enhancing the lives of those affected. The association provides information, education, advocacy and direct services to the community and those living with spina bifida and their families. Some of their services include annual walk-a-thons, holiday parties, emergency funds, *Crossroads* newsletter, first Saturday adult support group and numerous resources for families.

### Spina Bifida Association of America National Conference

800.621.3141

sbaa.org

The Spina Bifida National Conference offers exceptional medical sessions, practical workshops and memorable social events for kids, teens, adults and families. Each year the conference is held in a different city throughout the nation. Along with the conference, children of all ages with spina bifida and their siblings can participate in Kids!Camp programs. There are also special sessions for adults with spina bifida. The conference is a great place to meet other families, learn new information about spina bifida and have fun!

### ParentWISE

773.880.4119

childrensmemorial.org/parentwise

**Parent Wisdom In Shared Experience** is a Children's Memorial Hospital 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.



### **Sibshop**

Advocate Illinois Masonic Pediatric Developmental Center Sibshop  
3040 N. Wilton, 2nd Floor, Chicago, IL 60657  
773.296.8127  
siblingsupport.org

Sibshop Groups are for brothers and sisters of a person with special needs. Sibshops are a spirited 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.

### **Recreation and Sport 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. A good first place to start is by taking with your local community center or park district. There are also special recreation programs in various communities and many now offer a variety of adapted sports programs. Speak with your medical team and social worker for referrals to specific programs in your area.

### **Camp Independence: YMCA Camp Duncan**

847.546.8086  
ymcacampduncan.org

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.

### **Adolescent and Young Adult Tele-Conference Program**

513.467.9292  
sharonsellet@aol.com

The tele-program is an affordable and efficient means to get connected with people from across the United States and discuss various topics that affect adolescents and young adults with spina bifida all over the phone! There are two programs within the tele-program: 1) The nine-week series "Setting Your Sight on the Future: Strategies To Get What You Need and Most of What You Want" is a facilitated discussion centered on self knowledge, interdependence, and building your foundation (tools, tips, skills and resources). 2) Special Topics are one-night programs with experts — many from the Spina Bifida National Conference — speaking on a single issue and sharing their expertise with the tele-program audience. For more information or to register for the next session, contact Sharon Sellet.

### **First Saturday (SBAIL)**

773.444.0305  
sbail.org

First Saturday is a social support group for adults 18 and older with spina bifida and meets the first Saturday of each month at Anixter Village. The program does a variety of social events, guest speakers and a time to meet your peers.



## Rehab Life Skills

### Division of Rehabilitation Services (DRS)

800.843.6154  
dhs.state.il.us

The Division of Rehabilitation Services (DRS) operates 45 offices in communities throughout the state, as well as three residential schools serving students with disabilities, and a residential training facility for adults who are blind or visually impaired. The major programs offered through DRS are the Vocational Rehabilitation (VR) program, and the Home Services program (HSP). DRS also administer the Disability Determination Services program on behalf of the federal Social Security Administration.

### Center for Independent Living

Illinois Network of Center for Independent Living  
ilcil.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.

### Paratransit Services

847.364.7223

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 on fixed bus routes 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, you may request transportation to interview if needed.

### Illinois Circuit Breaker (People with Disabilities Ride Free)

Illinois Department on Aging  
1.800.624.2459  
cbrx.il.gov  
state.il.us/aging

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. If you are approved you will receive a postcard in the mail which you must take to your local Regional Transportation Authority office to receive your pass.

### Rehabilitation Institute of Chicago Transition Life Skills Group

312-238-1133  
www.ric.org

Rehabilitation Institute of Chicago offers a Transition Group for teens and young adults to address six life skills areas that focus on independence and caregiver involvement. The areas of concentration are medical information and care, household management, cooking, community integration, education and employment, and recreation and sports. The group meets weekly and is a hands-on group to teach these life skills. Speak with your medical team for a referral to the Transition Group.



Artwork  
created by  
Hollis, age 12

## 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 is most often a “stand alone” document, but it can form part of a Last Will and Testament. 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.

### Guardianship

Clerk of the Circuit Court – Cook  
[cookcountyclerkofcourt.org](http://cookcountyclerkofcourt.org)

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 financial 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 deterioration, 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.

### Power of Attorney (Healthcare)

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.

## 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.

### Rehabilitation Institute of Chicago (RIC) Adult Spina Bifida Clinic

312.238-1000  
[ric.org](http://ric.org)  
[lifecenter.ric.org](http://lifecenter.ric.org)

The adult spina bifida clinic at RIC is a multidisciplinary clinic with specialist doctors from neurosurgery, urology, orthopedics and rehab medicine specialists. The adult clinic meets the first Friday morning of each month. Most patients from Children's Memorial will transfer their spina bifida care to the adult clinic around 18-22 years of age. RIC has various resources such as the assistive technology, prosthetics and orthotics and vocational rehabilitation, which help individuals lead more independent and fulfilling lives. RIC also has the Life Center which is a valuable resource for families. RIC offers many programs for children, adolescents and adults.



# Timeline of Services for Children and Adults with Spina Bifida



Please note that 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.

| Birth-3 years old                                | 3-5 years old                                    | 6-13 years old                                   | 14-18 years old                                  | 18 years old and up                              |
|--|--|--|--|--|
| <b>BENEFITS AND INSURANCE</b>                    |  |  |  |  |
| Insurance/All Kids/Medicaid                      | Insurance/All Kids/Medicaid                      | Insurance/All Kids/Medicaid                      | Insurance/All Kids/Medicaid                      | Insurance/ Medicaid                              |
| Division of Specialized Care for Children (DSCC) | Division of Specialized Care for Children (DSCC) | Division of Specialized Care for Children (DSCC) | Division of Specialized Care for Children (DSCC) | Division of Specialized Care for Children (DSCC) |
| Supplemental Security Income (SSI)               | Supplemental Security Income (SSI)               | Supplemental Security Income (SSI)               | Supplemental Security Income (SSI)               | Supplemental Security Income (SSI)               |
| WIC  | WIC  |  |  |  |
| <b>EDUCATION AND EMPLOYMENT SERVICES</b>         |  |  |  |  |
| Early Intervention                               | Pre School Transition                            | School Age Education Services (IEP/504)          | IEP Transition Planning                          | Post high school plan                            |
|  |  |  | Vocation Rehabilitation (DRS)                    | Vocation Rehabilitation (DRS)                    |
|  |  |  | Work Incentive Planning (If have SSI)            | Work Incentive Planning (If have SSI)            |
| <b>DEVELOPMENTAL DISABILITY SERVICES</b>         |  |  |  |  |
| Division of Developmental Disability (PUNS)      | Division of Developmental Disability (PUNS)      | Division of Developmental Disability (PUNS)      | Division of Developmental Disability (PUNS)      | Division of Developmental Disability (PUNS)      |
|  | Respite Services                                 | Respite Services                                 | Respite Services                                 | Respite Services                                 |
| <b>SUPPORT AND LEISURE</b>                       |  |  |  |  |
| Spina Bifida Assoc. of IL Member                 | Spina Bifida Assoc. of IL Member                 | Spina Bifida Assoc. of IL Member                 | Spina Bifida Assoc. of IL Member                 | Spina Bifida Assoc. of IL Member                 |
| National SB Assoc. Conference                    | National SB Assoc. Conference                    | National SB Assoc. Conference                    | National SB Assoc. Conference                    | National SB Assoc. Conference                    |
| ParentWISE                                       | ParentWISE                                       | ParentWISE                                       | ParentWISE                                       | ParentWISE                                       |
| SibShops   | SibShops   | SibShops   | SibShops   | SibShops   |

(continued)



Artwork created by Hollis, age 12

| Birth-3 years old                        | 3-5 years old                           | 6-13 years old                          | 14-18 years old   | 18 years old and up                                     |
|--|---|---|---|---|
| <b>SUPPORT AND LEISURE (continued)</b>   |   |   |   |   |
|  | Recreation and Sport Opportunities      | Recreation and Sport Opportunities      | Recreation and Sport Opportunities                      | Recreation and Sport Opportunities                      |
|  |   | Camp Independence                       | Camp Independence                                       | Camp Independence                                       |
|  |   |   | Tele-Conference Program                                 | Tele-Conference Program                                 |
|  |   |   |   | First Saturday: SBAIL Adult Support Group               |
| <b>COMMUNITY AND LIFE SKILLS SUPPORT</b> |   |   |   |   |
| DHS Rehab Services                       | DHS Rehab Services                      | DHS Rehab Services                      | DHS Rehab Services                                      | DHS Rehab Services                                      |
| Local Center For Independent Living      | Local Center For Independent Living     | Local Center For Independent Living     | Local Center For Independent Living                     | Local Center For Independent Living                     |
|  |   | Para Transit Services                   | Para Transit Services                                   | Para Transit Services                                   |
|  |   |   | Circuit Breaker   | Circuit Breaker   |
|  |   |   | Rehab Institute of Chicago Transition Life Skills Group | Rehab Institute of Chicago Transition Life Skills Group |
| <b>FUTURE NEEDS PLANNING</b>             |   |   |   |   |
| Special Needs Trust                      | Special Needs Trust                     | Special Needs Trust                     | Special Needs Trust                                     | Special Needs Trust                                     |
|  |   |   | Guardianship  | Guardianship  |
|  |   |   | Power of Attorney (Medical)                             | Power of Attorney (Medical)                             |
| <b>HEALTHCARE PLAN</b>                   |   |   |   |   |
| Children's Memorial Spina Bifida Clinic  | Children's Memorial Spina Bifida Clinic | Children's Memorial Spina Bifida Clinic | Children's Memorial Spina Bifida Clinic                 | Rehab Institute of Chicago Adult Spina Bifida Clinic    |
| Other Pediatric Specialists              | Other Pediatric Specialists             | Other Pediatric Specialists             | Other Pediatric Specialists                             | Other Adult Specialists                                 |
| Primary Care Doctor (Pediatrician)       | Primary Care Doctor (Pediatrician)      | Primary Care Doctor (Pediatrician)      | Primary Care Doctor (Pediatrician, Family Medicine)     | Primary Care Doctor (Family Medicine, Internist)        |
|  | Pediatric Dentist                       | Pediatric Dentist                       | Pediatric Dentist                                       | Adult Dentist   |
|  |   |   |   | Women's Health Doctor                                   |

