POPULATION SPECIFIC FACT SHEET

What to Know When Assisting a Consumer with Spina Bifida

This fact sheet will help Navigators identify issues unique to consumers with Spina Bifida (Myelomeningocele) to assist them to make decisions related to their healthcare coverage.

Q1. What do I need to know about Spina Bifida?

A. Spina Bifida (SB) is a complex birth (neural tube) defect that affects the brain and spinal cord. In SB, part of the spine – usually the lowest part – does not fully form, leaving a gap in the back, which causes the spinal cord or the covering of the spinal cord to be exposed. This results in permanent damage to the spinal cord, leaving the person with varying degrees of paralysis (severe muscle weakness) from the level of the lesion and below. Main issues involved in Spina Bifida: paralysis (severe muscle weakness) usually in lower limbs causing mobility problems, orthopedic problems, tethered spinal cord, neurogenic bowel and bladder, brain issues (hydrocephalus, chiari malformation).

Q2. What type of health care providers does someone with Spina Bifida need access?

A. Most people with SB require multi-disciplinary care in the following areas: neurosurgery, urology and orthopedics. Some children experience precocious puberty and require endocrinology. After puberty, men's and women's sexual health care is also a priority. Some people with SB have seizure disorders and require care from a neurologist. People with SB are at high risk for Osteoporosis, obesity and other chronic conditions that the general population faces. Therefore, non SB health maintenance is as important as care for SB related issues. Therefore, although an interdisciplinary team approach is recommended the individual with Spina Bifida needs a PCP to help coordinate care (think medical home!). Individuals with SB have all of the other health issues as individuals without SB such as asthma, viruses, cholesterol issues, blood pressure issues, etc.

Q3. What are some prescription needs that someone with Spina Bifida may have?

A. Anticholinergic medications for treatment of neurogenic bladder-Botox injections into the bladder to increase bladder capacity and reduce pressures, stool softeners to manage neurogenic bowel- some people with SB need anti-epileptic medications for epilepsy.

ADHD medications in childhood, And in adults, anti-depressants and anxiolytic medications are commonly taken.

For children who experience precocious puberty, puberty blocking medications may be taken until the child is chronologically of age to experience normal puberty, then those medications are stopped.

Although most adults with SB are fertile and can produce children, men may have difficulty achieving erection and orgasm due to poor sensation in the lower limbs. Therefore, they may take medications or receive other medical care for erectile dysfunction.

Q4. What type of therapies (for instance, physical, occupational, speech, or others) and/or devices (durable and/or disposable) could someone with SB require?

A. People with SB often require physical therapy (PT) or occupational therapy (OT) services, which may be covered by healthcare plans. They usually also wear braces on their legs (Ankle Foot Orthosis or AFO's or Knee Ankle Foot Orthosis or KAFO's).

The young individual with SB may require neuropsychology assessments periodically. (Usually at transitions->to kindergarten ->to Middle school- >to high school). A common result of hydrocephalus is learning differences/disabilities and understanding the results of the testing can help guide educational strategies. If the student is fortunate enough to attend college the learning disability needs to be documented (within 3 years). Many health plans pay for the initial diagnostic assessment only. These can cost between $1,200-$2,000.

The ongoing therapies and devices are complex and vary across the lifespan. They are detailed in the information sheet *SB and the Spine* available here: http://spinabifidaassociation.org/infosheets/sb-and-the-spine/.

Q5. What other services and supports, which are not generally medically arranged therapies and devices, are typically required by persons with SB? Are these arranged and financed in some private health insurance plans or in some Medicaid programs?

A. Because of poor sensation and lower limb paralysis, they are at high risk for skin breakdown and need to assess their skin each day for areas of redness or changes in appearance or temperature. They need to avoid the following: prolonged rubbing, pressure, friction, shearing, wetness, burns and blistering, poorly fitting clothes, sitting too long or sitting too long in one position.

The following is a list of needed items that are usually covered under insurance plans: continence supplies, catheters, absorbent undergarments, cecostomy irrigation bags, wheelchairs, tire replacements, portable ramps, protective seating to help reduce pressure ulcers, shower chair. Wheelchairs are usually covered for replacement every 3 years in a growing child. Once they are fully grown they don't qualify for a new wheelchair without good reason (old one cannot be repaired) and insurance will only cover maintenance and repairs on the old chair.

Neuropsych and urology assessments are also required and usually covered under insurance plans

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Q6. Are there any other unique medical needs that someone with SB should consider when evaluating a health plan?

A. People with SB require a health plan that allows them to receive multi professional care on a regular basis throughout life. Many people with SB have Medicaid and/or Medicare and receive Social Security Disability benefits.

Although many will work, they will require numerous surgeries (orthopedic, urologic, neurosurgical) beginning at birth and throughout life. They will also require durable medical equipment, catheters, and are at very high risk for having allergic reactions to products that contain latex; so they should not be exposed to latex in the home, school, work or medical environment.

In addition to surgeries, there are procedures to assess renal function (uro dynamics, renal ultrasounds, possible deflux injections) which may be needed, along with equipment such as c-pap and bi-pap, and diagnostics such as MRI's (when shunt function is in question).

Q7. What types of accommodations I should consider when I'm planning to meet with someone with Spina Bifida?

A. Most people with SB will need "space" accommodations. They will ambulate with walker or crutches, or use a manual or motorized wheelchair. Some people will have a service dog. They will need rooms that have wider doorways that accommodate large wheelchairs and bathrooms that meet ADA standards.

Although people with SB generally have normal intelligence, they may have cognitive impairment, also called cognitive dysfunction. It may cause problems with higher level thinking, decision making, initiation, impulse control, and attention. Those difficulties may negatively impact learning, especially in math and reading. In school, children will have an Individualized Education Plan http://spinabifidaassociation.org/project/individual-education-plan/

Social issues also prevail. Later is life there may be problems with maintaining relationships and employment. High support and a clear plan is recommended throughout the transitional years from teenage into adulthood, both in the SB clinic and at home/school. At this time, there are very few Spina Bifida clinics that provide adult focused care, so that will need to be part of the planning/accommodations process.

Access is the primary concern here (steps, narrow walkways - esp for power chairs that are wider) Bistro tables and bars are a challenge. *Some theaters will allow a companion to an individual who uses a wheelchair free admission*

Remember to use “Disability Etiquette”. Interact sitting if possible versus looking down at the individual. Do not move the wheelchair unless asked to do so. Do not speak for the individual when placing an order, etc. To read more about disability etiquette, check out our fact sheet on the topic here: http://www.nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/fact-sheet-17/.

Q8. Are there any resources you would recommend to obtain additional information about Spina Bifida?

- What is Spina Bifida? http://spinabifidaassociation.org/what-is-sb/
- FAQ’s about Spina Bifida http://spinabifidaassociation.org/faqs-about-sb/
- SB Information Sheets http://spinabifidaassociation.org/info-sheets/
- Research Center http://spinabifidaassociation.org/research-center/

You can also read:

- The textbook on Pediatric Rehabilitation. It is intended for medical professionals but you can extrapolate a lot of useful info.
- Living with Spina Bifida: A Guide for Families and Professionals, 2nd Edition, by Adrian Sandler.