



Understanding – Disabilities in Women and Girls with Blood Disorders

A Better understanding of what is classified as a disability can be studied by the statistics obtained from Social Security Administration's (SSA) Blue Book for childhood hematological disorders

Key Listings Relevant to Pediatric Bleeding Disorders

1. 107.08 – Disorders of Thrombosis and Hemostasis : This includes conditions like hemophilia, von Willebrand disease, and platelet function disorders. A child may qualify if they experience:
 - At least three hospitalizations in a 12-month period,
 - Each lasting 48 hours or more, and
 - Related to spontaneous bleeding or bleeding requiring transfusion.
2. 107.05 – Hemolytic Anemias: While more relevant to conditions like sickle cell disease, this listing includes severe anemia that may overlap with bleeding disorders if chronic blood loss is involved.
3. 107.10 – Bone Marrow Failure Syndromes : This applies to rare inherited disorders that may cause bleeding due to low platelet counts or clotting factor deficiencies.
4. 107.17 – Hematological Disorders Treated by Bone Marrow or Stem Cell Transplantation : While not common for most bleeding disorders, this listing is relevant for severe or overlapping conditions requiring transplant.

What This Tells Us

SSA recognizes that recurrent, severe bleeding episodes, especially those requiring hospitalization, can be disabling in children. However, the bar is high: documentation must show frequent, serious complications that interfere with normal development or daily functioning.

The listings also emphasize the need for:

- Definitive lab tests confirming diagnosis,
- Physician reports detailing the impact on the child's health and activities,
- And evidence of functional limitations, such as mobility issues or school absences.

Disabilities can be

- Functional
- Physical
- Emotional

Functional Disabilities:



Chronic Anemia and Fatigue: These refer to how a medical condition restricts a person's ability to perform basic physical or cognitive tasks. For bleeding disorders, relevant limitations might include:

- **Mobility impairments:** Difficulty walking, standing, or using limbs due to joint damage or chronic pain
- **Fatigue and stamina issues:** Resulting from chronic anemia or frequent bleeding episodes
- **Fine motor limitations:** Trouble with tasks like writing or buttoning clothes if joints in the hands are affected
- **School attendance and participation:** Frequent absences due to hospitalizations or recovery from bleeds
- **Residual Functional Capacity (RFC):** SSA uses a tool called the Residual Functional Capacity (RFC) assessment to evaluate these limitations. It looks at how long a child can sit, stand, walk, lift, or concentrate, and whether they need assistive devices like braces or wheelchairs.

Physical Disabilities:



Musculoskeletal Damage:

Although joint bleeds are more common in boys with hemophilia, girls who are symptomatic carriers or have rare factor deficiencies can also experience joint and muscle bleeds. Repeated episodes can cause chronic pain, limited mobility, or even permanent joint damage.

Emotional and Mental Health Disabilities / Considerations

- *Reproductive Health Complications:*

Undiagnosed bleeding disorders can lead to severe postpartum hemorrhage or complications during gynecologic procedures. In extreme cases, girls and women have undergone unnecessary hysterectomies due to unrecognized bleeding disorders.

- *Psychosocial and Educational Impact:*

The stigma and unpredictability of symptoms like HMB can lead to anxiety, depression, and school absenteeism, which may affect long-term educational and social development.

Chronic illness in childhood:

can also lead to emotional and behavioral challenges, which SSA takes seriously. These may include:

- Anxiety or depression: Due to the unpredictability of bleeding episodes or social stigma
- Social withdrawal: Avoiding peers or activities out of fear of injury or embarrassment
- Cognitive or attention issues: Often linked to fatigue or missed school
- Adjustment disorders or PTSD-like symptoms: Especially if the child has experienced traumatic medical events

SSA evaluates these under mental disorder listings (like 112.00 for children), focusing on how the condition affects:

- Learning and applying information
- Interacting with others
- Concentrating and completing tasks
- Managing emotions and behavior

How This Applies to Disability Claims:

Even if a child doesn't meet a specific medical listing, they may still qualify for benefits if their combined physical and emotional limitations significantly impair daily functioning. This is especially relevant for girls with bleeding disorders who experience both joint damage and psychosocial stress.



Requirements to qualify to get assisted devices:

Medicare Requirements (for children and adults)

To qualify for mobility assistive equipment (MAE) such as canes, walkers, manual or power wheelchairs, or scooters, Medicare requires that:

- A doctor must prescribe the device, stating it is medically necessary for use in the home.
- The individual must have a health condition that significantly limits mobility, making it difficult to perform daily activities like bathing, dressing, or using the bathroom—even with a cane or crutch.
- The person must be able to safely use the device, or have a caregiver who can assist.
- The home must be accessible for the device (e.g., wide enough doorways for a wheelchair).
- Both the doctor and the equipment supplier must be enrolled in Medicare and accept assignment.

ADA and Public Access

Under the Americans with Disabilities Act (ADA), individuals with disabilities are allowed to use mobility devices—including wheelchairs, walkers, and even powered options like scooters or Segways—in public spaces. Businesses and government facilities must accommodate these devices unless there are legitimate safety concerns.

Clinical Criteria for Coverage

The Centers for Medicare & Medicaid Services (CMS) uses a clinical algorithm to determine eligibility. It considers:

- The person's mobility-related activities of daily living (MRADLs)—like toileting, feeding, and grooming
- The physical and psychological function of the individual
- The living environment, including layout and caregiver support

This means that even children with bleeding disorders who experience joint damage or fatigue may qualify if their condition limits their ability to function independently at home.

How Children Qualify for Assistive Devices

1. Medical Evaluation and Prescription

A pediatrician, hematologist, or rehabilitation specialist must document that the child's condition—such as joint damage from a bleeding disorder—limits their ability to perform age-appropriate activities (e.g., walking, dressing, attending school). This documentation is essential for insurance or Medicaid approval.

2. Functional Assessment by a Multidisciplinary Team

Pediatric cases often involve an interdisciplinary team: physicians, physical and occupational therapists, school specialists, and sometimes social workers. They assess:

- Mobility and endurance
- Fine and gross motor skills
- Participation in school and play
- Emotional and behavioral needs

3. Individualized Education Program (IEP) or 504 Plan

If the child is in school, assistive devices may be provided or supported through an IEP or 504 Plan under the Individuals with Disabilities Education Act (IDEA). This ensures access to mobility aids, communication tools, or classroom accommodation.

4. Funding Sources

- Medicaid (EPSDT): The Early and Periodic Screening, Diagnostic, and Treatment benefit mandates coverage of medically necessary assistive devices for children under 21.
- Private Insurance: Often requires prior authorization and detailed justification.
- State Assistive Technology Programs: Many states offer loaner programs or grants.
- Nonprofits: Organizations like UnitedHealthcare Children's Foundation or Variety – the Children's Charity may help cover costs.

5. Training and Follow-Up

Once a device is approved, pediatric therapists provide training to ensure the child can use it safely and effectively. Follow-up evaluations are crucial to adjust for growth or changing needs. You might find the American Academy of Pediatrics' clinical report especially helpful—it outlines how pediatricians can prescribe and advocate for assistive technology, and how families can navigate funding and support systems.

Pediatric wheelchair

Purpose:

Used when joint damage, chronic pain, or fatigue limits a child's ability to walk safely or independently.

Types:

- Manual wheelchairs: Lightweight and often foldable; ideal for children with upper body strength or caregiver support.
- tilt-in-space wheelchairs: Allow for pressure relief and posture support—helpful for children with joint pain or fatigue.
- Power wheelchairs: For children with severe mobility limitations who need independent movement.

Key Features:

- Adjustable seat depth and height to accommodate growth
- Custom cushions to prevent pressure sores
- Postural supports (headrests, lateral supports, harnesses)

Qualification Process:

- Requires a prescription from a pediatrician or specialist
- Must demonstrate that the child cannot perform daily activities without it
- Often involves a seating evaluation by a physical or occupational therapist

Pediatric Orthotic Braces

Purpose: Support weakened joints, correct alignment, and prevent further damage from joint bleeds or muscle imbalances.

Common Types:

- AFO (Ankle-Foot Orthosis): Stabilizes the ankle and foot; used for foot drop or ankle instability
- KAFO (Knee-Ankle-Foot Orthosis): Extends up the leg for more severe joint involvement
- SMO (Supramalleolar Orthosis): Shorter brace for mild ankle instability
- Custom splints or boots: For foot deformities, plantar flexion, or post-bleed recovery

Features to Look For:

- Lightweight, breathable materials
- Adjustable straps for growth and comfort
- Custom-molded fit to prevent skin breakdown

Qualification Process:

- Requires a detailed evaluation by a pediatric orthotist or rehab specialist
- Must show that the brace improves function or prevents deterioration
- Often covered by Medicaid, private insurance, or school-based services

Where They May Need Help with Daily Chores

Girls with joint instability (especially in the knees or ankles), chronic pain, or fatigue from anemia may struggle with:

- Carrying heavy items (e.g., laundry baskets, school bags, groceries)
- Standing for long periods (e.g., cooking, brushing teeth, showering)
- Reaching or bending (e.g., picking up toys, cleaning, dressing)
- Fine motor tasks (e.g., buttoning clothes, tying shoes, opening containers)

These limitations can be subtle but cumulative—leading to frustration, dependence, or even injury if not addressed.

Supportive Tools and Strategies

According to Steps for Living and the Hemophilia Outreach Center, here are some practical supports that can help:

Adaptive tools:

- Long handled reachers or grabbers
- Shower chairs or stools for grooming
- Ergonomic kitchen tools with easy grips
- Velcro clothing or magnetic fasteners

Environmental modifications:

- Lowered shelves or hooks
- Anti-fatigue mats in kitchens or bathrooms
- Lightweight cleaning tools (e.g., cordless vacuums)

Task simplification:

- Breaking chores into smaller steps
- Using rolling carts or baskets
- Scheduling rest breaks between tasks

Family and peer support:

- Creating chore charts that match ability levels
- Encouraging shared tasks to reduce isolation

The Foundation for Women & Girls with Blood Disorders also emphasizes the importance of educating caregivers and teachers about these needs—so girls aren't penalized for needing help, but instead empowered with tools and understanding.