



## Gap Analysis / Statistics of Disabilities in woman and girls with blood disorders

Unfortunately, there's no centralized dataset that breaks down how many children with hematological disorders listed under SSA codes 107.08, 107.05, 107.10, or 107.17 go on to develop disabilities or require assistive devices like wheelchairs. However, here's what we can piece together from available national data:

### What We Know from Broader Disability Statistics

- According to the U.S. Census Bureau, 7.2% of U.S. households with children reported having at least one child with a disability in 2019.
- Among children with disabilities:
- 18.4% had ambulatory difficulties, which may include the use of wheelchairs or mobility aids.
- 78.6% had cognitive difficulties, often overlapping with physical conditions.

While this doesn't isolate hematological disorders, it suggests that mobility limitations are a significant concern in the pediatric disability population.

## Hematological Disorders and Disability Risk

From clinical literature and SSA criteria:

- 107.08 (Thrombosis and Hemostasis Disorders): Children with severe hemophilia or von Willebrand disease may develop joint damage (hemarthrosis), leading to chronic pain and mobility impairment. These children are the most likely among the four categories to require orthotic braces or wheelchairs.
- 107.05 (Hemolytic Anemias): Conditions like sickle cell disease can cause pain crises, fatigue, and avascular necrosis, especially in the hips—sometimes necessitating mobility aids during flare-ups or post-surgery.
- 107.10 (Bone Marrow Failure Syndromes): These rare disorders (e.g., Fanconi anemia) often involve multi-system complications, including fatigue, growth delays, and immune suppression. Assistive devices may be needed during treatment or recovery phases.
- 107.17 (Post-Transplantation): Children recovering from bone marrow or stem cell transplants may experience temporary or long-term mobility limitations, especially if complications like graft-versus-host disease affect muscles or joints.

## What's Missing

There is no published national registry that tracks:

- The percentage of children with these specific SSA-listed disorders who develop long-term disabilities
- The number prescribed wheelchairs, braces, or assistive technology
- This gap underscores the need for targeted surveillance and research—especially since many of these children fall through the cracks of general disability data collection.

## Why does the gap exist

- Lack of awareness of the problem,
- Lack of familiarity with /or the guidelines,
- Non-agreement with the recommendations,
- Inability to overcome the inertia of previous practice, and
- Presence of external barriers to perform recommendations
- Lack of Knowledge competence
- Lack of time to assess or counsel patients
- Cost / Insurance/reimbursement issues
- Patient Compliance Issues

## What can be done to improve this gap

Creating Checklists and strictly adhering to them. Checklists can be individualized for

- Educators
- Parents and care givers
- Healthcare Providers
- Patients