

Caring for a Child or Youth With Special Healthcare Needs

Caring for a child or youth with special healthcare needs can be incredibly rewarding and challenging. One of the first steps in this journey is learning how to navigate the healthcare system and access community resources. This can take time, energy, and patience, but these initial investments will have beneficial results: identifying the child's specific healthcare needs and determining how to best care for them.

Special Health Care Needs Defined

The Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) defines children and youth with special healthcare needs (CYSHCN) as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

It is important to note that children and youth may be at risk for additional or more complicated challenges if they have experienced trauma.

Child-Focused Care and Support

As a caregiver, you are already well aware that all children are unique individuals and so are their special health care needs. Learning about each child's specific healthcare needs will provide you with insightful information and knowledge on

how you can provide the best support and care.

A child's healthcare needs will change throughout their developmental stages; therefore, you may find it especially helpful to form and develop an interactive partnership with the child's primary healthcare provider.

Seeking out opportunities to continue learning, using relevant resources, and connecting with others caring for children or youth with similar conditions are all additional ways to help support the child in your care. A few places to start include the

[Children and Youth with Special Health Care Needs Program](#), [Well Badger Resource Center](#), and [Wisconsin Wayfinder Children's Resource Network](#).

Medical Home & Care Notebooks

The “*medical home network*” is a care philosophy supported by the American Academy of Pediatrics. Its premise is that all children should

have a medical home where care is accessible, family-centered, coordinated, continuous, comprehensive, compassionate, and culturally effective.

You can request that your doctor's office assign a care coordinator who will work to help organize services for the child. The doctor's office can also provide ongoing coordination and comprehensive care. While



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not all doctors' offices in Wisconsin have this service yet, you can visit the [Wisconsin Medical Home Initiative](#) website for more information and resources.

The medical home initiative promotes the idea of using the Well-Visit Planner at [WellVisitPlanner.org](#). This is basically an online care notebook of medical information that helps parents maintain an ongoing record of the child's care, services, providers, and notes.

This will help you track information such as:

- Medical history
- Health care providers
- Insurance information
- Key information in case of needed emergency care
- Appointment logs
- Medication logs
- Tracking lab work and/or procedure results
- Care plans
- And much more

Being an Advocate

When caring for a child or youth with special health care needs, you automatically become that child's advocate. This new responsibility demands that you learn about the child's condition or special needs by attending meetings, talking with the child's physician (s) and therapist (s), and possibly even doing additional research to learn. Advocating for a child with special health care needs includes:

- Working closely with the child's caseworker and support team to keep everyone involved with the child's care up to date.
- Seeking out support, if needed, in connecting with the child's birth family to obtain pertinent medical history, as well as to keep them updated on the child's health.

- Understanding and coordinating Medicaid services.
- Choosing a primary care provider for the child in your care (in some cases). If you can select this physician, you will want to verify that they will accept Medicaid and are available and willing to advocate for the child.
- Maintaining the placement packet and keeping records. Special note for foster parents or relative caregivers: obtain as much information as possible on medical, dental, developmental, immunization, and mental health records, as well as care received while the child was in other homes.
- Working collaboratively with the school system, meeting with teachers and therapists, and attending Individual Education Plan (IEP) meetings.

Asking Questions

One of the best ways to communicate with the child's doctor and healthcare team is by asking questions.

- Think ahead. Because time is limited during medical appointments, you may feel less rushed if you prepare any questions you may have before the appointment.
- Write your questions down to help you remember what you need to ask.
- Bringing a copy of your questions to the doctor will ensure your concerns are addressed should the appointment be rushed. If enough time is not available to address all of your concerns, the doctor can have a copy of the list and get back to you. Alternatively, you might also send a list of questions before your appointment for the doctor to address when you see them. This can often be done through the electronic medical chart (for example, MyChart) if you can access it.

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Connecting with Others

Connecting with other families with children with similar health issues can be extremely helpful. The [Regional Centers for Children and Youth with Special Health Care Needs](#) in your area may have information about support groups you might want to attend or join.

Hospitals, clinics, and family resource centers sometimes host parent support groups. Below are some family-to-family organizations that can help:

- [Parent to Parent of Wisconsin](#) supports parents of children with special needs through a one-to-one connection with another parent who has a similar experience and knows firsthand the feelings and realities of having a child with special needs. You can call them at 888-266-0028.
- [Family Voices of Wisconsin](#) is a network of families with children and youth with special health care needs and/or disabilities and those who work on their behalf. Family Voices provides information, training, and leadership opportunities for families and advocates for public policy and system change to improve the lives of children with special healthcare needs and/or disabilities. You can reach them at 608-220-9598.

Caring for children and youth with special healthcare needs can be challenging. It is important to remember that you are not alone and that many resources are available for you, your family, and the child for whom you care.

Please feel free to contact the Wisconsin Family Connections Center for additional support or resources. We are always here to help and can provide you with tools for your caregiver toolkit.



Resources

From the [Resource Library](#)

- *The Child with Special Needs*, by Stanley Greenspan & Serena Wieder

Additional Resources

- [Children and Youth with Special Health Care Needs \(CYSHCN\) Program](#)
- [Well Badger Resource Center](#)
- [Wisconsin Department of Health Services, Community Resources for Families and Children in Wisconsin](#)
- [American Academy for Pediatrics—National Resource Center for Patient/Family-Centered Medical Home](#)
- [Wisconsin Wayfinder Children's Resource Network](#)
- [Taking Care of the Family](#)
- [Wisconsin Family Ties](#)

Training From [Champion Classrooms](#)

- [About Wisconsin Wayfinder Children's Resource Network](#)
- [Introduction to Services and Resources for Children With Disabilities: A Family Voices "Did You Know" Learning Session](#)