



## Fostering a Child or Youth with Special Health Care Needs

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

### Special Health Care Needs Defined

Children and youth with special health care needs (CYSHCN) are defined by the Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) 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."

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 foster parent, 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 health care needs will provide you with insightful information and knowledge on how you can provide the best support and care.



A child's health care 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 health care provider.

Seeking out opportunities to continue learning, use relevant resources, and connecting with others who are caring for children or youth with similar conditions are all additional ways you can 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](#), or the [Regional Centers for Children and Youth with Special Health Care Needs](#) in your area.

If you are caring for a child for whom there are identified needs for special accommodations, such as a wheelchair accessible home or car, resources from

Continued on page 2



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[Medical Home Portal](#) may be particularly helpful.

### Medical Home & Care Notebooks

The “*medical home network*” is a care philosophy supported by the American Academy of Pediatrics. The framing belief 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 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 idea of a *care notebook* comes directly from the medical home initiative. A care notebook is a notebook of medical information that helps parents maintain an ongoing record of the child’s care, services, providers, and notes.

A care notebook can include 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

[This website](#) has more detailed information

to help you create and build your care notebook.

### Being an Advocate

When you are caring for a child or youth with special health care need, you automatically become that child’s advocate, as well. 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 in order 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 are able to select this physician, you will want to verify that they will accept Medicaid and are available and willing to advocate for the child in your care.
- Maintaining the placement packet and keeping records. 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 foster homes.
- Working in a collaborative fashion 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



Continued on page 3



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the child's doctor and health care 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 in advance of the appointment.
- Write your questions down to help you remember what you need to ask.
- Bring a copy of the doctor. This way, should the appointment be rushed and if enough time is not available to address all of your concerns, the doctor has the list and can get back to you. Alternatively, you might also send a list of questions in advance of your appointment for the doctor to address when you see them.

### Connecting with Others

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

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

- [Parent to Parent of Wisconsin](#) provides support to parents of children with special needs through a one-to-one connection with another parent who has a similar experience and who knows firsthand about the feelings and realities that come with having a child with special needs. 888-266-0028
- [Family Voices of Wisconsin](#) is a network of families who have 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

health care needs and/or disabilities. 608-220-9598

Fostering children and youth with special health care needs is not an easy endeavor. It is important to remember that you are not alone and that there are a multitude of resources available for you, your family, and the child for whom you care. One of the greatest things about fostering a child with special health care needs can be that unexpected smile or twinkle in their eyes. **You** are the reason for that smile. Every single day, you are making a positive difference in the lives of all the children and youth you care for.

Please feel free to reach out to the Coalition for additional supports or resources. We are always here to help and can provide you with tools and resources for your foster parenting tool kit.



### Resources

From our [Lending Library](#)

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

### Online 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](#)



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