



In this together

**Interventions to support
medically complex warriors and families**



**Division of
Aging**

Care plans and care maps: Innovative tools to improve the care of children living with medical complexities.

The need to support

- » Children with medical complexity are a population who may depend on highly specialized care from multiple providers in numerous settings to optimize independent living at home.
- » Improved communication along with medical and social coordination is an essential component of delivering family centered care that is of high quality and efficiency for children with medical complexity.
- » Objective evidence to support the use of care plans and care maps is evolving and supports the development and use of care plans and care maps that are child- and family-driven.

Supporting parents

Care planning for medically complex children

- » A care plan is a written document that outlines the major medical issues and care needs for a specific child and is created by the waiver provider(s) and health care provider(s) in collaboration with the family. The document should be consistently modified to meet a variety of changing needs, including an emergency care plan and advanced directives.
- » They facilitate transition through the health care system, enhance care coordination and manage health information across sites of care.
- » They are a useful tool for providers and parents that centralizes and focuses care of the child and centralizes exchange of information.

Understanding care maps

- » A care map depicts complexity of care and life for children living with medical complexity and their families.
- » It is a pictorial way to describe the individual needs, strengths and assets of a family and to provide the holistic view of a child in their family and community.
- » Providers may be able to use the family created care map to help avoid duplications or gaps in services, prioritize among multiple activities and identify care coordination and communication needs.
- » Care maps provide a visually compelling tool to advocate for improved integration of services for children with medical complexity and their families.

Supporting parents to help medically complex children thrive

Parents are frontline public health workers—they nurture and support, supervise and teach healthy habits, make sure their child is safe and supported in their community and help their child get the education and health care they need.

But for children who experience chronic, complex health needs, their care extends beyond usual parenting responsibilities. And just as kids have medically complex needs, their parents have needs too. Theirs are often unmet and muted. For instance, about 17% of parents feel their health has worsened since their child's diagnosis, and three out of 10 parents report feelings of chronic sorrow.

Caregiving impact on parents

Home nursing care is often warranted—but, too often, not reliably available—for children with medical complexity who live with serious and sometimes life-threatening conditions and who usually depend on medical technology for their well-being and safety. When these children reside at home, parents or guardians are expected to provide medical care during many, or even all, hours of the day and night. Parental duties might include administering medication, providing enteral tube feedings or parenteral nutrition and perpetually monitoring the child's needs, among other tasks. Many of these caregiving activities involve sustained attention and physical labor and must be performed multiple times each day.

What does the data tell us?

All of this work adds up. Caregivers of CMCs spend on average up to 52 hours per week providing health care at home, with more complex conditions reporting higher average time spent. This workload far surpasses the norm for parents of healthy children; between 2013 and 2017, U.S. adults with children younger than 18 years spent an average of only 3.03 hours per week providing physical care for household children. In addition to caregiving duties, many parents of CMCs must also stay employed for regular income and also to keep their family's health insurance. Parents may also have to manage other demanding responsibilities, such as raising other children, caring for elders, maintaining a home and looking after their own health. With all these time demands and weighty responsibilities, no wonder that these parents experience high levels of anxiety and depression, sleep deprivation and insomnia, along with feelings of exhaustion and burnout.



How care managers implement support interventions for minor children

In order to offset financial stressors, care managers discuss the following options with parents that are available through the waiver:

Options

1. The Aged and Disabled waiver and Traumatic Brain Injury waiver both provide services of attendant care and home and community assistance.
 - » A parent/ guardian may hire an aide through a personal services agency or home health agency to care for their child.
 - » A parent/guardian may be hired by a personal services agency or home health agency to provide direct care to their child.

When this option doesn't work

2. If the child's parent/guardian is the owner of the personal services agency or home health agency, the parent may not be reimbursed through Medicaid for providing care to their minor child.
3. A parent may not provide care to a minor child within structured family care.
4. A parent may not provide care to a minor child within consumer directed attendant care.

Reimbursable activities

5. Attendant care and home and community assistance reimburse for unskilled activities. We know parents perform skilled care for their children. If a parent is performing skilled care, the waiver does not reimburse for those activities.

Service hours

6. The number of hours is not the focus!
7. Just like any other aide, a care manager and provider coordinate opportunities for clients (even parents as paid staff) when there is conversation as a team: provider, care manager and parent talk about what activities will be performed.
8. It is important to understand the activities not as a function of audit and justification, but to ensure the child's needs are met and the parents' needs are supported financially or through respite care.

Other services

9. Care managers will talk to parents about other available services (on the waiver or community resources) to best meet family needs.
10. Integrated service plans are what the Division of Aging would like to see!
11. Specialized medical equipment may support families when care managers focus on child-centered equipment, such as a tomato high-chair or P-pod postural support system for mobility and posture. Also, interactive activity boards are a great way to strengthen mind and body. While these items are not specifically listed in the "specialized medical equipment" waiver service, they do fall into categories of equipment, such as "self help device," which is reimbursable by Medicaid.

The “why” of reimbursing parents to provide care

12. Personal service agencies and home health agencies have a mechanism to provide daily oversight of staff through the Division of Aging as well as the Indiana Department of Health.
13. FSSA audit intervenes if care managers have concerns about fraud. The Division of Aging does not support the focus of care management to be audit and/or fraud prevention.
14. The waiver is a mechanism to wrap supports around clients and their families. The Division of Aging is dedicated to not just meeting base level needs of clients and their families, but integrating social and health supports in a way that paves the way for people to thrive in their communities of choice.

Parenting medically complex children can present many joys and challenges. For parents who don't have many resources, these challenges may be harder to tackle. Parents may need help facing those challenges. The Aged and Disabled waiver and Traumatic Brain Injury waiver provide financial support, services, training and education to parents so that children may thrive in a supported home.

Care mapping can be a useful approach to elucidate why quality medical and social coordination is needed for medically complex child. At the level of the individual, care mapping is a visual, detailed account of patient and family needs and strengths and demonstrates the interactive relationships among the various team members and resources at both the micro- and macrosystem level. A care map portrays the family in the center of the multiple people, processes, interventions, organizations, and methods by which communication and interventions must occur. Training providers and families in care mapping can be a valuable exercise to actively engage families and activate teams.

Strategies for implementation

Care plan

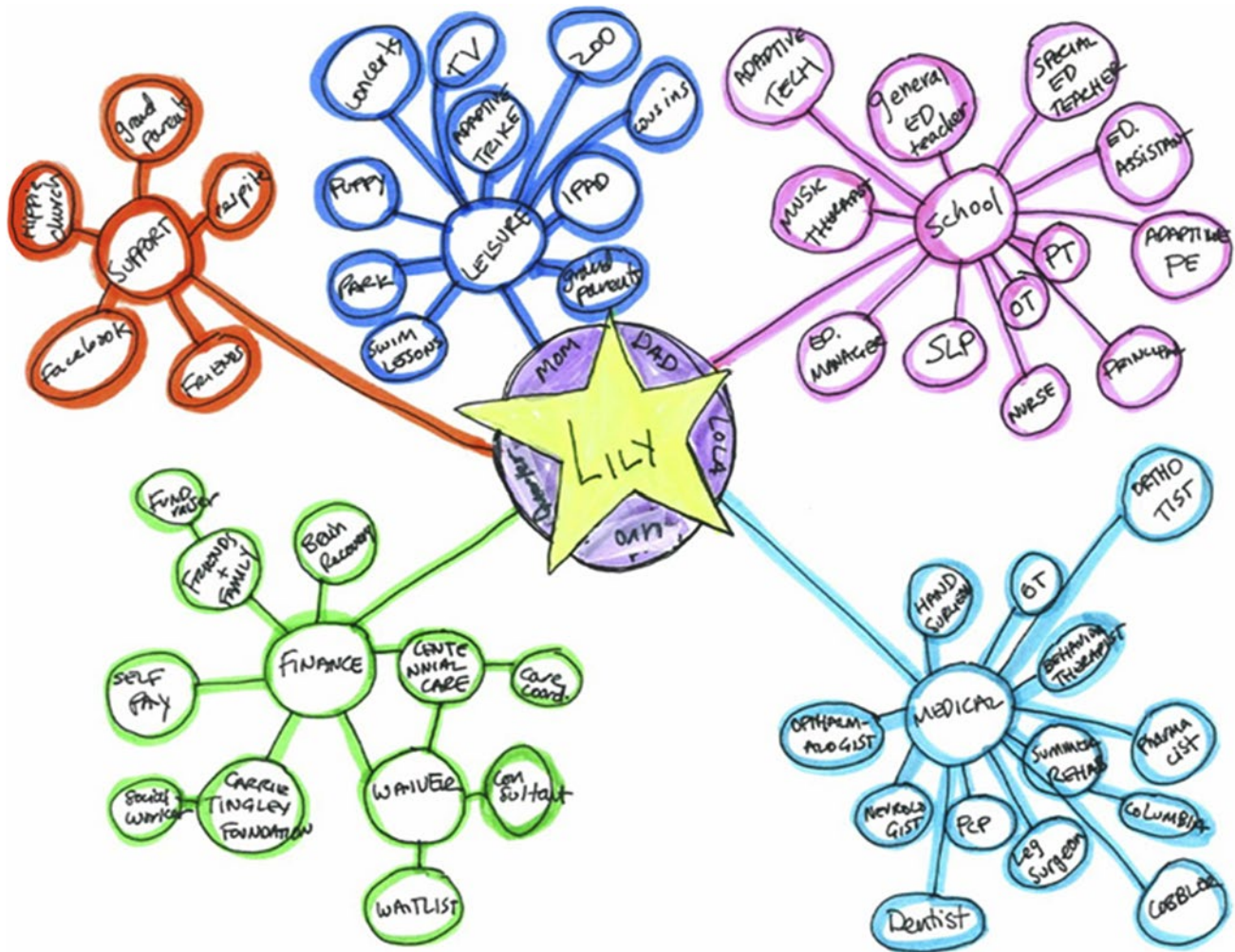
- » Ensure you include a description about the child's development, functional status, social situation and communication strategies.
- » Collaborate with parents throughout to ensure that information is accurate, valuable and consistent with information they wish to share.
- » Update care plan regularly and share with appropriate providers.

Care map

- » Work with family to support them in care map creation.
- » Review care map with creator to ensure full understanding.
- » Use care map content to support care coordination and advocacy work with families.



Care map example



A care map for Lily at age 9.

Notice that, in addition to being incredibly chaotic in appearance, there are some key areas that are 58 professionals or supporting relationships being managed by the parent to support Lily, who is a medically complex warrior.

One year later, those relationships have been reduced to 46 through careful consultation with Lily's primary care physician, waiver providers, school, and social activities.

There were unnecessary redundancies in care that were never seen before and the care map created a clear roadmap to remove excess activities, bills and obligations.

Additionally, Lily's parents resigned from many of the advocacy activities that did not directly appeal to their interests and focused on increasing leisure and recreation. Lily's condition didn't change at all, but the family was able to visualize and then build a more organized life for the entire family.