

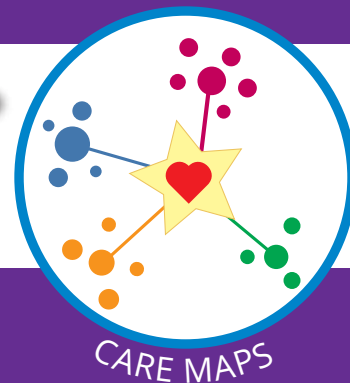
# Stepping Stones



## Parent Education & Advocacy Leadership Center

Promoting inclusion and access  
in education and healthcare

Empowering families and  
young adults across PA



### Care Maps

Care for children and youth with special health care needs (CYSHCN) can be challenging to coordinate given the complexity of systems and involvement of multiple services and providers. Families are often responsible for:

- making appointments
- getting children to therapies and appointments
- filling prescriptions
- resolving insurance problems and finding ways to pay for uncovered expenses
- serving as the backup home health nurse

These responsibilities may take hours to coordinate and can be exhausting, especially in addition to running a home and maintaining employment.

A care map is a family-centered visual tool that illustrates the network of care for CYSHCN, including medical, educational and other support systems. (See example on side 2.) It is powerful to visualize the services, linkages, and interconnections for children and young people who have complex medical issues. It provides an overview and the details that can be used to understand the value of:

- working together to most effectively meet needs,
- tackle barriers, and
- drive ongoing services.

Cristin Lind first created a care map when she was asked to explain what was involved in raising her child with special needs. Families create the care map and use it to guide discussions with providers to talk about the impact on the child and the family. A care map should be created in a way that is meaningful to the family. Families that have more than one child with special health care needs can create one overlapping care map.



**Tip: Create your care map in a way that is meaningful to you and easy to update as changes occur.**



A care map can be used to start a conversation with providers, teachers and community agencies to educate them about the added time and stressors involved in raising a child with special health care needs. Families may need to decrease or stop working which can create financial challenges, increase strain in relationships and/or cause basic needs to go unmet.

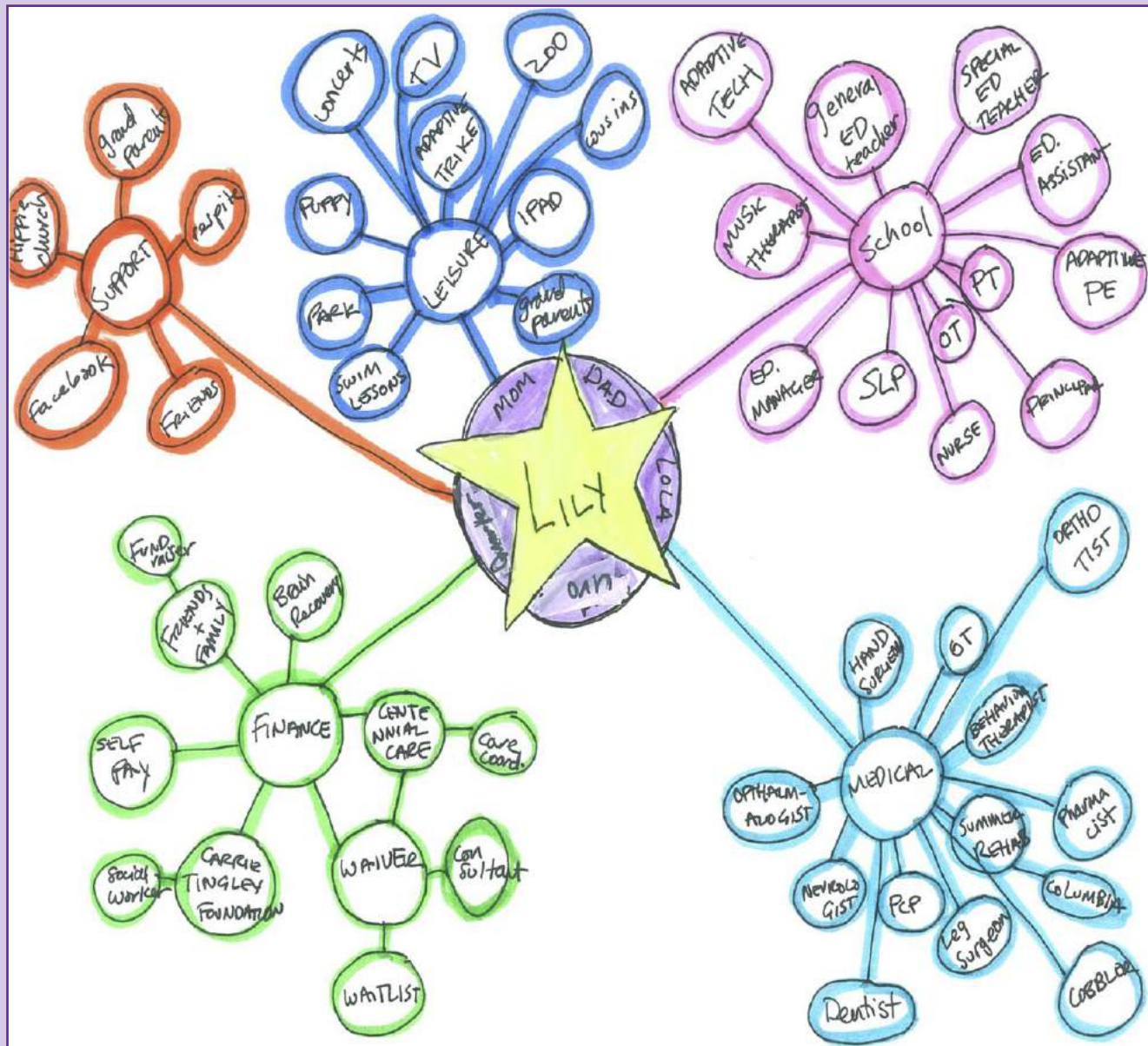
#### Care Maps can be used as a tool to:

- Arrange and maintain services
- Prioritize
- Identify and avoid duplications and gaps
- Coordinate care and create a Care Plan
- Identify potential referrals
- Prepare for the future and transitions
- Advocate and educate others

***A care map is a tool that has the power to have a positive impact in shaping outcomes for the individual and their family.***

**Kidspiration** (see Resources on Side 2) and other concept mapping apps or templates can be used to create care maps with technology.

## Care Map



Used with permission from Cristin Lind, <http://www.cristinlind.com>.

## Resources

1. Kidspiration: <https://bit.ly/33gytCy>
2. University of Toronto: **Care Plans and Care Maps: Innovative Tools to Improve the Care of Children with Special Health Care Needs** <https://bit.ly/3hwxq1b>
3. Boston Children's Hospital: **Organizing Care and Relationships for Families: Care Map** <https://on.bchil.org/2OLEb70>
4. Children's Wisconsin: **A Picture Paints a Thousand Words: Care Maps Help Families Identify What Matters Most** <https://bit.ly/2WLN1WK>
5. Lucile Packard Foundation for Children's Health: **Family Stories** (photos, information, and care maps from real families) <https://bit.ly/2BleUNZ>
6. American Academy of Pediatrics: **Care Coordination for Children With Medical Complexity: Whose Care Is It, Anyway?** <https://bit.ly/3ePrOle>

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Contact the PEAL Center for additional information.  
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