

Care Mapping: A How-To Guide for Patients and Families

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Families raising children with special needs have long acted as the primary care coordinators for their children, connecting the dots between home, health care, school and the community. Acting as “air traffic control” between health care providers, home care workers, child and respite care, teachers, specialists and community agencies can add considerable stress and time to parenting, cause families to miss work or work less, strain relationships or cause needs to go unmet.

Professionals can help relieve some of this stress and help families be more effective by partnering with them to coordinate and plan care. We have developed a tool, the care map, to assist families and the professionals they partner with. Although it was initially created for families raising children with special needs, it can also be used for anyone of any age or level of needs to make partnering with professionals more effective.

What is care mapping?

Care mapping is a process which guides and supports the ability of families and care professionals to work together to achieve the best possible health outcomes. In its most developed form, care mapping is a family-driven, person-centered process which highlights a family's strengths and communicates both the big picture and the small details of all of the resources needed to support a child and their family. It provides a comprehensive snapshot of a family's needs, and enables the care team to appreciate how each of these aspects relates to each other.

How do I make my care map for my child or family member?

Here are some step-by-step instructions for creating your own care map:

1. Starting with a blank piece of paper and a pencil, draw a circle in the middle of the paper which represents your child and a ring around him/her depicting your family.
2. Coming out from the center, begin depicting the individuals or organizations that are part of your child's team, grouping them into broad categories and subcategories in a way that makes sense to you and to the people you will want to share the map with. Some examples of categories might include: Medical, school, recreation/community/social, legal/financial, social services, advocacy and information, spiritual, transition, work, housing, transportation and caregiver support. It may take several attempts before it feels complete. Don't worry about getting it 100% right.

3. You may need or want to re-write it using different colors, symbols, and line shapes to communicate additional data such as barriers, support, or unmet needs. It's best to keep your process simple. You can use a photo of your child or family in the center.
4. Include your child/youth in the care mapping process. They may even be able to make their own. It will likely look very different from the one you make, but that can be informative.
5. Lastly, make copies of your care map and/or scan it. Having an electronic version will allow you to share it by email with care team members if you need to.

How do I use my care map?

You can use your care maps can to:

- reflect on your own experience and journey. Many families who have created their own care map express a feeling of satisfaction and pride at the supports they are managing for their child when they can see them all at once.
- assess the Big Picture. Is there anything on the care map that surprises you? How do you feel when you look at it? Is there anything missing?
- communicate with care team members, family and friends. Share it with trusted members of your child's care team, including family, caregivers, healthcare or education providers, or anyone who you think could benefit from the big picture or who you partner with to make decisions about care.

What else should I think about when making or using a care map?

One common pitfall in making a care map is to make it so complex and detailed that it becomes difficult for someone other than you to read or understand. Keep it simple, or create different versions depending on the need. It can be tempting to include details about other important responsibilities to drive home the message that you are juggling a lot of responsibilities, but adding things unrelated to your child's care can dilute the care map's impact.

Another common pitfall is using mind-mapping software or some other technological tool that isn't flexible enough to create an expressive care map. While software can add many additional features to your care map, use it only if you are extremely proficient. We advise that you at least begin on paper. Many people have expressed that the handwritten aspect of the care map serves an important reminder that it is created by families.

How can I learn more about care mapping?

Further training materials are being developed to support families who have children with special needs to develop the skills to create and use their own care maps. We are also beginning to work with primary

care providers, subspecialty providers and community care providers to learn how to effectively engage families in a discussion of care coordination utilizing this tool as a focal point.

In addition, we are in the process of developing tools to measure the experience of families and professionals engaged in care mapping.

For the latest information on care mapping, please visit www.childrenshospital.org/care-coordination-curriculum/care-mapping.

References

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