

Care Mapping: A How-To Guide for Professionals

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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.

Who can use care mapping to partner with families?

Anyone aspiring to support families by assisting them with the coordination of care in any domain of life may find care mapping beneficial, including nurses or nurse practitioners, social workers, community health workers, educators, advocates, medical assistants, physicians, family navigators, family support workers, or peer support providers.

How can I use care mapping to partner with and advocate for children/youth with special needs and their families?

We know that optimal outcomes are often the result of effective relationships between team members. This applies in social and in business environments. It is especially true in health care. We know that the provision of care coordination was positively associated with patient- and family-reports of “receipt of family-centered care, experiencing partnerships with professionals, satisfaction with services, ease of getting referrals, fewer out-of-pocket expenses and family financial burden, fewer hours per week spent coordinating care, less impact on parental employment, and fewer school absences and ED visits.” (Turchi et al. 2009).

We recommend that you encourage families to create their own care map which should be integral to the process of receiving care from you. Feel free to share the Family Use tool: “Care Mapping: A How-To Guide for Families.” [hyperlink to pdf] While it may be tempting to create the map for them, the goal of this process is to empower the family to share their perception of their child’s care needs and care team. Make every effort to have them drive the process. Keep your suggestions general and supportive. The care mapping process is designed to deepen your shared sense of partnership and the family’s sense of efficacy; both of these factors will make it easier to have a discussion with the family about adding information as it becomes relevant over time.

Be careful not to infer the overall quality of care or resources based on the number of circles on the map. More circles can be positive when it means that there are adequate supports in place, or it can simply imply that the child’s needs are very complex. Assessing the families’ perception of the value to them of each resource will be an important function in the provision of care coordination.

Once a family has created a care map, you can then use it to partner with them to help them do things like avoid duplications or gaps in services, prioritize among multiple (if not competing) activities, and identify care coordination and communication needs.

Care mapping aligns with the core functions of care coordination. (The Commonwealth Fund, 2009). It has the potential to play a critical role in optimizing outcomes in evolving accountable care organizations and integrated delivery systems. Care mapping can be a tool to ensure optimal outcomes of:

- Referral management
- Family/ patient experience
- Utilization tracking
- Communication across providers

Care maps can also be used in teaching, training and policy advocacy by effectively communicating the complexity involved in raising a child with special needs.

What is Next for 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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