

The way forward: A framework that details how to support family caregivers of children with disabilities



What is this study about?

Families are essential to helping children with disabilities achieve their best possible outcomes – yet there are few formal services available to support them in that role.

“Family-centred care” is meant to support not only the well-being of the child, but also of the family. Navigating the medical system, coordinating services, interacting with various providers, advocating, and engaging in day-to-day life can be overwhelming for parents and negatively impact their well-being and ability to support their children’s care.

The research team conducted a scoping review to understand and identify what types of family-oriented services were offered in different countries. From there, they built a framework of most helpful services.

What is a ‘scoping review’?

A scoping review looks at many types of studies to better understand a topic. It may include published (e.g., journal articles) and unpublished work (e.g., posters, presentations, other documents).



What is family-centered care?

Family-centered care is built on partnerships between parents and health-care professionals. It recognizes that families are the constant in a child’s life and must be supported in their efforts to care for a child with a disability.



What did the research team find?

After searching global databases in a five-year timespan, the researchers found only 36 studies that described services that supported families.

The types of support fell into four categories:



- Educational programs and information days



- Support groups led by peer mentors, parents or providers



- Psychosocial support including respite breaks, counselling and coaching



- Help navigating the coordination of care for their children

The research team used these findings to create a visual framework that shows areas where family caregivers could be supported. This design could help pediatric rehabilitation organizations strategize the right services that could help each family address their unique needs.

The framework shows the type of services that can support a family's needs for information, education, training, support groups, psychosocial services, and care coordination – as well as how they can be provided.



What this means for caregivers

Providing caregivers with support is necessary and caregivers should consider their own health and well-being, alongside of their child's care. This review found that certain support services do exist and are useful for families caring for a child with a disability.

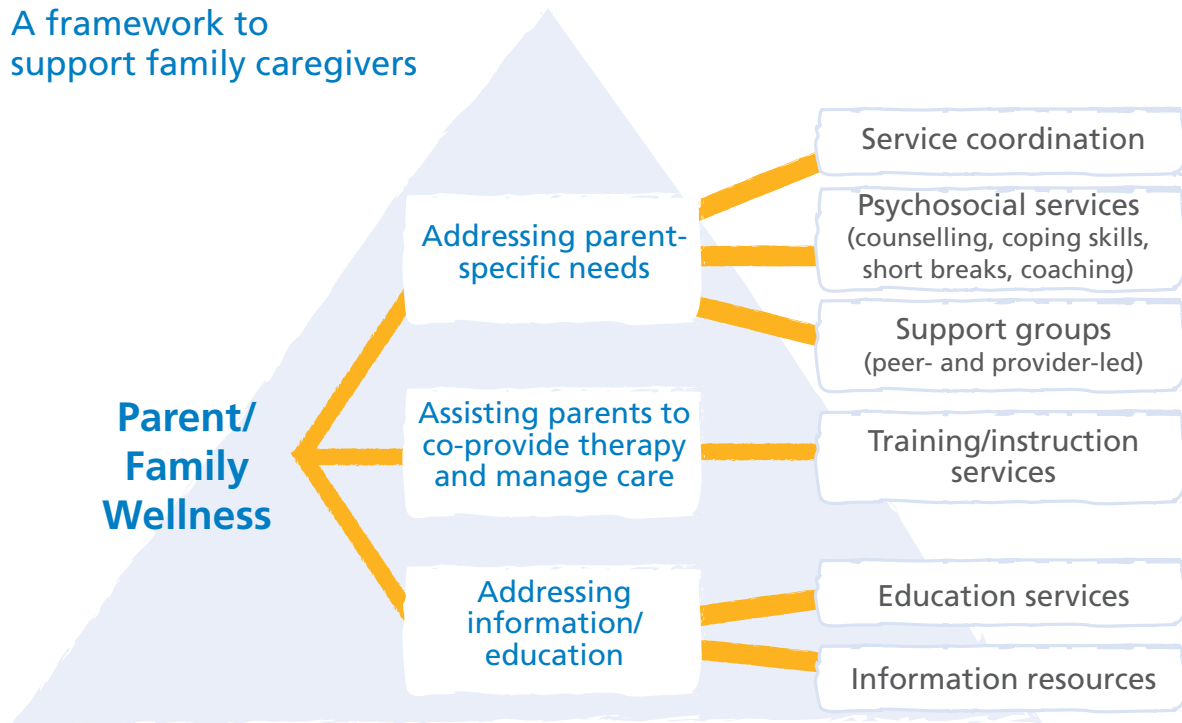
While some organizations provide support such as Holland Bloorview's "Care for the Caregiver" program, this paper clearly reveals an ongoing need for pediatric organizations to develop more sensitive, flexible services that will meet the needs of these families.

The road to change begins with families and institutions understanding which services can support various caregiver needs. Organizations must develop policies that foster the development of support services such as peer support groups. Families in turn, must be supported in advocating for those support services.

From family member who read this study

"I was pleased with this framework. It's comprehensive and it touches on the different types of needs. It describes services that organizations around the world have implemented and seen success with, which others should model."

A framework to support family caregivers



For more information

Find the [abstract here](#) or visit your local library:

King, G., Williams, L., & Han Goldberg, S. (2017). Family-oriented services in pediatric rehabilitation: a scoping review and framework to promote parent and family wellness. *Child: Care, health and development*, 43(3), 334-347.

- View [Dr. King's researcher profile](#)

