

Network helps kids with complex special needs

COMMON GOOD: The second in a series of stories examining a unique way to fund social services

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Colleen Camelford has a portable suction machine slung over her shoulder while her husband, Ian, packs an oxygen tank on his back. His arms are wrapped around their 27-month old son, Tyson, recipient of the oxygen.

The family of three meanders through a unique parent information fair designed for them and hundreds of other families in Simcoe County with children with special needs. Tyson has a rare genetic condition and spent the first two years of his life at Toronto's Hospital for Sick Children.

When he finally came home in April, the search for services to match his many needs began.

"We've lost that connection with the hospital resources, and you don't know where to start when you're on your own," says Tyler's mom.

This ongoing trek led the Camelfords from their Beeton home to this fall event in Barrie.

The first-time fair was a collaboration between the Children's Treatment Network of Simcoe York and a committee of parents of children with special needs, bringing together the myriad of groups that provide different services to the community.

The Camelfords zeroed in on a room dominated by scores of baskets containing application forms. Application forms -- they're the lifeline for many of these families.

"I'm always filling out out forms. It's a full-time job," says Theresa Meininger-Saunders, a parent and event organizer. "Organizing my daughter's health care . . . is a full-time job."

She's not kidding.

The 200 people who mill about the fair throughout the afternoon are in various stages of their search. Some are just realizing there's a huge learning curve -- first to figure out what, specifically, their child needs and how to get it, then to keep up on it all as the child grows and evolves. That involves learning the system and its nuances, paying attention to its many changes.

To be sure, the search is continuous no matter where in the learning curve these parents fall.

The point of the fair was to help these already overwhelmed parents by offering shortcuts, piggybacking onto the research that's already been done.

"As a parent of a special needs child, I know I've spent a lot of time," says Meininger-Saunders. "It's a struggle.

"A lot of times parents just can't find the time and they're overwhelmed."

The Children's Treatment Network opened five years ago to fill a huge void for children with complex special needs.

"This is a culmination of 10 years of a group of very committed families and service providers . . . advocating and pushing for these services," says Louise Paul, CEO of the Children's Treatment Network. "They wanted to build on the work that had been done to date."

While most other places in the province were serviced by Children's Treatment Centres, the idea for the new service for York Region and Simcoe County was to move away from having one central building and duplicating services that, for the most part, already exist.

Instead, there are nine offices scattered throughout the various communities. This is where the families start when they look for the services their children require.

By going into each community, the centre is able to put its little pot of money for the various services like speech therapy into the programs that are already there and expanding upon them, instead of duplicating them. The idea is to link up the special needs kids with the various services they require.

"We flow our dollars to enhance their services so they serve children who come through our intake," expanding upon existing services instead of recreating them, says Paul. "It makes sense to leverage what is already there."

At the end of the day, says Paul, the network is one of the most efficient organizations of its kind in the province because so much of its \$10.6 million goes directly into services for children. And it is run by a staff of seven.

In Barrie the Children's Treatment Network operates out of the Common Roof in Barrie. It's the only one of its nine locations where it has some ownership. The relationship fits right in with the overall plan to tap into and work with other groups with a similar clientele. And, again, the idea is to make that dollar stretch to limit wait list lengths and get kids what they need as soon as possible.

And like the other social service organizations under that roof, innovative use of money is key in a time of stagnant budgets and large growth. The network receives the same amount of government funding it did when it was launched five years ago, even though its service area has among the highest growth rates in the province.

One of the advantages of being the new kid on the block is that the Children's Treatment Network was able to use the latest in technology in getting established. And that included developing electronic records so that parents don't have to repeatedly tell their story and allows those providing the services overviews of the families they're working with as well as their needs.

This single plan of care covers was established following all the legal obligations, including parental permission.

The fair, which, if only for an afternoon, brought all those groups and a whole bunch more of the others together, available to those families in search of answers. The partners in the building simply agreed there was a need and they all came together for the first time to meet it.

"I think it's a great way for parents to navigate through all this stuff," says Tyler's dad, whose feet hit the ground running in search of help when Tyler came home. "There's a lack of interest from governments. There's a big need."

"We could never have done that without the support of our partners," says organizer Leanne Weeks. "It takes a village to raise a child and it takes more than one agency to help these kids."

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