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The Ottawa Children's Treatment Centre. Family-Centred Health Service Exemplifies Community Partnership & Innovative Care

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Treatment Centre : Innovative support for special kids and their families

Written by Kirsten Franklin



Imagine that you have a 14 year old son, Jacob, a gifted athlete, who suddenly has a massive stroke and is left unable to walk. Imagine giving birth to a baby who has experienced oxygen deprivation resulting in a diagnosis of cerebral palsy. Or, imagine being a parent who is increasingly anxious about seeing a child retreat into his own world, not speaking or interacting with others. Unless you have or know a family facing such challenges, chances are you know little about the Ottawa Children's Treatment Centre (OCTC). However, according to legions of parents, the OCTC is, as Jacob's father Louis puts it, 'the most well-kept secret' in Ottawa.

Doctors Emma and Wade Gofton, an obstetrician/gynecologist and an orthopedic surgeon, have two children who have cerebral palsy. Both of their children have received extensive therapeutic support at the Centre and they chose to live and practice medicine in Ottawa in large part due to the OCTC. For the Goftons, the OCTC has given them peace of mind, security and a strong faith in both the health care and educational systems. As doctors, they have seen other treatment centres in Ontario and for them, none match the OCTC. Emma can hardly put into words what the OCTC School and Centre have meant to her family. "It is just the best".

The OCTC (www.octc.ca) was founded in 1951 to provide specialized care for children with physical, developmental and associated behavioural needs. Its mission is to provide individualized support, in partnership with the community, to maximize integration and independence for children and their families. While its biggest physical site is next to CHEO, it has satellite buildings and offices in Kanata and in Renfrew. At these sites, 180 professionals work together, in both English and French to support each child and family with a wide range of rehabilitation and functioning therapies. The Centre serves families from Pembroke to Cornwall.

Close to 3300 children and youth residing throughout Eastern Ontario are clients at the Centre. Roughly half of these clients are six years of age or under, with the remaining

half aged from seven to eighteen years of age, or older. The diagnostic profile shows that the three largest groups have Autism Spectrum Disorders, developmental delays and disabilities for a variety of reasons or Cerebral Palsy. Smaller groups of children and youth have special speech and language needs, chromosome anomalies or brain injuries.

The OCTC staff says it finds inspiration in its children and families and is humbled each day to see a grace and resilience in each of them. These families, in turn, find true inspiration in the OCTC professionals who are passionate advocates, devoted and respectful members of the child's health team and true caregivers in every sense of the word.



Adjusting to "A New Normal"

Families with children who have any of these diagnoses are understandably in varying degrees of crisis. Like a mobile hanging above a crib, when one part of it is pulled sharply, the other parts circle around to regain a sense of balance. For this reason, once services with the OCTC begin, professionals work with collaborative

and interdisciplinary approaches to provide family-centred care. The more support there is for the family, the stronger the chances are for the child.

To this end, the OCTC's Social Work Services offer a slate of support groups where common experiences can be shared and where family and clients can connect. Family resource workers bring knowledge and resource information. There are groups for parents dealing with new diagnoses, such as Autism, Down Syndrome, physical and developmental disabilities. There is a grief recovery outreach program, a grandparent workshop and a sibling group, as well as a parent support group for teenagers with Asperger's Syndrome/ high functioning Autism. There is a group for teenagers themselves, called Teens First which gives youth with physical disabilities opportunities to discuss, share and learn about issues relevant to their experiences.

The Early Childhood Program includes a preschool for children with complex physical disabilities and there is even an Infant Development Program. Young children are assisted by a team of professionals depending on their needs. Kristine McKeague is the

mother of three year old Penelope who has cerebral palsy and is medically fragile. While at an OCTC appointment where Occupational Therapist Laura Bradley was assisting Penelope with hand function and finger extension, Kristine said that when first learning of her daughter's diagnosis, the OCTC helped her to navigate through a dark time. OCTC staff not only developed strategies to best help Penelope, but the Centre was an immense support for Kristine and her family. Providing real options and answers at a time when "common sense seems to go out the window" was invaluable.

Access

The OCTC does everything it can to facilitate access to assistance for families. In fact, home support is often necessary and quite frankly, welcomed. Pauline Jodouin is an Early Childhood Consultant, often the first responder to new cases, who sees that her primary role is to focus on support and help parents to navigate in a world which has often become overwhelming and frightening. For Pauline, trusting partnerships with parents and family-centred consultancy is vital. Her greatest joy is she sees children waiting at the windows when she comes to visit.

The Centre also offers playgroups that are aimed at helping children but they also go a long way in providing parents with opportunities to meet with other parents and to share the common journey that they share.

Out of Home Respite Programs

For families with medically fragile and/or technologically dependent children who require 24-hour care, the Centre, with the City of Ottawa and funding from the Ministry of Children and Youth Services, provides bilingual day programs. Referrals can come from the Community Care Access Centre (www.champlain.ccac-ont.ca) case managers, doctors and social workers. Registered Nurse Coordinator Anna Buchanan leads a team which gives one-on-one recreational respite opportunities each Saturday. Her greatest satisfaction comes from being able to provide "much-needed and well-deserved respite [for parents] from the loving yet exhausting responsibilities their children require every day." The day programs have included clowns, musicians and even reptiles. Sabrina Passe is the mother of Jedidiah who has cerebral palsy and is medically fragile. With no family in Canada, this respite has given her the greatest gift of time. Similarly, Julie Chapados feels completely secure in leaving her son Benoit at the respite program for children with Autism. These programs are lifelines for parents.

Autism and the Getting Started Services Clinic

If you see that your child has developmental delays and that an Autism disorder might be the cause, the OCTC can conduct a formal evaluation. The Early Childhood Program and the Life Span Program provides services to help. (However, media attention and growing knowledge about Autism disorders have resulted in increased awareness so waiting lists do exist for diagnostic services.)

In the Throne Speech delivered on March 3, 2010 (www.speech.gc.ca), Prime Minister Harper stated that the Government “will look to innovative charities and forward-thinking private-sector companies to partner on new approaches to many social challenges”. One only has to look to Suzanne Jacobson to find an example of an innovative approach to charities.

In 2002, Suzanne Jacobson became worried about her 16 month old grandson, Alex. He did not speak, nor did he respond when his name was called. Increasingly concerned, assurances that boys develop later did not sit well with her family. However, they soon discovered that waiting lists for assessments and diagnoses were long. With more and more evidence revealing that early intervention was of utmost importance, Jacobson lost sleep at nights, wondering what could be done about getting information and pre-diagnosis services to families, even before a child was formally assessed. In 2007, she approached OCTC CEO Kathleen Stokely who had been challenged by this issue and by funding. Together a partnership evolved where Jacobson formed QuickStart (www.quickstartautism.ca), which would raise funds that would help support a new

Getting Started Services Clinic, which would open in 2008.



These services offer parents access to a multidisciplinary team to address concerns and offer discipline-specific strategies while they are waiting for their child's developmental assessment. Professionals like Elaine Hendry, Cecile Bisson and

Laura Bradley offer strategies and support in areas such as communication, socialization, play skills, self help and behaviour. After an interview with an Early Childhood Specialist, parents have access to group sessions with rotating specialists

who are available to give parents information in a wide variety of related fields. The Clinic saw 200 children in its first 17 months. For Jacobson, what was absolutely amazing was CEO Kathleen Stokely's positive leadership and the willingness of the Ottawa Children's Treatment Centre to shift thinking and partner in this innovative problem-solving exercise. According to Hendry and Bisson, this pioneering clinic is becoming a model for other Children's Treatment Centres in Ontario.

The OCTC's Life Span Program uses rehabilitation teams to help children, youth and adults with developmental disabilities. Here, School-Aged and Adolescent Services provide treatment and includes an innovative recreation and leisure program and gives support for school aged youth.

Jacob and Virtual Reality Physiotherapy

Jacob Doyle had an acquired brain injury associated with a stroke just after finishing his grade 9 year. Jacob spent eight months at CHEO, two of which were in a coma, and was released to go home ten months ago. An OCTC team consisting of a physiotherapist, occupational therapist, a social worker and a speech and language pathologist were immediately put into place for him. With paralysis on his left side, Jacob initially could not walk, had impaired balance and speech difficulties. Thanks to Jacob's tenacious efforts, (he is now 16), his family and his team, he is now able to walk on a Litegait treadmill with a harness, and his endurance, strength and balance are consistently improving. He is able to communicate and is now attending high school. Physiotherapist Marie Brien also uses an intensive virtual reality program to help Jacob improve his balance and mobility. The GestureTek Interactive Rehabilitation and Exercise system provides games that immerse Jacob's body into a virtual world to interact with on-screen images and objects.

With a green screen background, he faces a camera and a television screen where he can see himself as a soccer goalie, reaching to catch balls coming his way. Jacob loves these virtual reality games and the progress that he is making with them is astonishing. Jacob's father, Louis knows that the OCTC "will be there as long as Jacob keeps progressing and we hope that that will be forever." Months ago when Jacob met Mike Fisher of the Ottawa Senators, he made a deal and said that if he would be able to walk, the Senators would have to win the Stanley Cup. Now the burden is on the Senators.

The OCTC School (primary level) and the Special Education Program are for children who have a physical disability and associated complex communication, developmental and/ or learning disabilities. A variety of therapists work with the children during the school day. The ultimate goal is to have children leave with a method of communication

and with a sense that “there is a place for you in your next school.” Principal Leslie Walker’s pride in the School’s increasingly independent children is palpable. Its greatest strength, Walker feels, is that it offers an intimate setting where a teacher can learn a student’s needs and can quickly see potential. Getting children to achieve their reading and writing goals, and reassuring them that “we are going to get there” are vital in preparation for life after the School. Every day, parents receive notes on their child’s daily progress. Emma Gofton feels that the dedication of the OCTC School is second to none. There, she says, her children are nurtured, loved, fostered and helped to become independent beings. For her daughter Aislinn, who attended the OCTC School for four years, the School gave her the invaluable skills that she needed to blossom at her new school when it was time to leave. Her brother Tait currently studies there.

With therapeutic support, assistive technology also plays an important role. Children are taught to use augmentative technology where, for example, big button-like switches are installed which the child can tap by hand or with a head movement to move cursors, enabling them to type.

Jan Heneberry is an Educational Liaison teacher whose job it is to work with OCDSB school teams to help students with special needs make the transition to new schools. Also involved in the Life Span Program, her heart and soul are with adolescents, who she meets with each week. She is also an important support and sounding board for parents. Often messages are left for her in the middle of the night. In the morning she finds solutions. For her, the most important thing for these children and parents is to be heard.

To ease access to over 50 local agencies and community groups, Heneberry began an annual Transition Resource Fair. Six special needs areas are included: day programs, residential programs (including the Rotary Home), education (including local School Board services), financial support, health and housing. Local organizations such as the Autism Society, the March of Dimes, and the City of Ottawa Special Needs Recreational Services are also invited to connect with parents seeking information.

The Assistive Technology Program offers services aimed to help children communicate using augmentative or alternative technological methods. Seating and mobility services are also offered. Elaine Kerr is the Assistant Coordinator of Technology Services and helps to run the OCTC Lending Library which loans and adapts toys for children as part of this program. Clients have access to 3000 items at no cost. For example, if parents want to buy a Dora the Explorer doll, they can have it adapted with a switch for very small cost. Work in this Program, Elaine says, is to customize any toy, educational tool

or software to enable each child to become integrated into daycare and school environments.

Volunteers

Over 150 volunteers each year help increase opportunities for clients to reach their goals. Many volunteers are university, college and high school students who are interested in health services and in pediatric rehabilitation. Others are grandparents and passionate stroke survivors like Darcy Quartermaine. Activities are varied and combine a variety of skills, from helping with respite programs and swimming programs to woodworking, building customized desks and sewing, where volunteers help to sew vests and blankets weighted with aquarium gravel for children with Autism.

The OCTC Foundation

Pat Shapiro, CEO of the OCTC Foundation (www.octc.ca/foundation) works to seek funding through strategic giving for research and special projects such as the Recreation and Leisure Service, which nurtures life skills. The OCTC's biggest corporate supporters are the Minto Group, the Ottawa Citizen and the TD Bank Financial Group.

In the end, the OCTC's inclusiveness is its hallmark. Seeking every influence that can affect and help children or youth — from medical and therapeutic to community and family participation — the OCTC is a place which inspires all who are connected to it. Together children and youth, their families, professional support teams and the regional community make the OCTC a place that is life-changing, life-giving and life-affirming.

For further information about access to OCTC programs and services, contact the OCTC at www.octc.ca or call 613-737-0871.