

REPORT to MPPs

Ontario Association of Children's Rehabilitation Services | FEBRUARY 2007



Brody Daigneau attends preschool at John McGivney Children's Centre in Windsor.

Parent lobbies for full and timely service for children

By Michelle Strutzenberger
Children with disabilities in Ontario can't be subject to financial restrictions in terms of the service they require, says Bobbi Holte. "Kids can't wait for service and they need full service," she says.

Holte, whose daughter Sydnie receives a range of therapies from KidsAbility, believes that complete funding for children's treatment centres is critical to ensure early intervention and full treatment.

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Parent fears loss of direct therapy services

By Craig Anderson
The addition of new annualized funds in 2006 allowed the Prism Centre for Audiology and Children's Rehabilitation to continue functioning as a family-oriented centre providing a high level of direct therapy services, and Paula Grail wants to see that continue.

In addition to sitting on the centre's board for two years, Paula has a son, Carson, who has cerebral palsy and has been receiving multiple forms of therapy – occupational, speech and language pathology, physiotherapy, and various recreational treatments - at the Chatham-based centre for the past four years.

She fears that without additional funds the centre will be forced to become more assessment and consultation-based, with

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New funds could help 24,000 children

By Michelle Strutzenberger
The Ontario Association of Children's Rehabilitation Services is asking the provincial government for additional annualized funding to help 24,200 children and youth with disabilities in Ontario.

OACRS has identified that Ontario's Children's

Treatment Centres (CTCs) need \$9.4 million to reduce wait times and \$11 million to ensure full CTC service for each child.

Wait times for treatment at CTCs are a major concern, as they are at health-care facilities across the provinces. On September 30, 2006, 5,000 children

with disabilities were waiting for therapy, 25 per cent more than on September 30, 2005.

Increased wait lists can be attributed to a number of factors, says Vicky Earle, CEO of OACRS. Improved screening of babies is identifying issues earlier, children with dis-

abilities are living longer, population growth is placing increased demand on some CTCs, and some hospitals are diluting out-patient services.

Not only is the number of children waiting considerable, but also the length of time they are waiting

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'We appreciate this government's understanding of the needs of children with disabilities'

Last year the Ministry of Children and Youth Services (MCYS) invested an additional \$10 million annually to help children and youth with disabilities. Now 4,000 more young people are able to receive the services provided by children's

treatment centres (CTCs).

"We're very pleased," says Vicky Earle, CEO of the Ontario Association of Children's Rehabilitation Services (OACRS). "We appreciate this government's understanding of the needs of children with

disabilities." She adds that the CTCs are now "working very hard to make sure the funds are benefiting the children as quickly as possible."

This past year saw some other important developments for children's rehabili-

tation services in the province, according to Earle.

A second major development was the launch of an Outcome Measures Program by OACRS, with funding from MCYS. The program is designed to

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Newest CTC faces funding challenges in expanding services

By John Driscoll

Leeann Whitney became a member of the founding board of One Kids Place in North Bay in 2003 because she wanted to see changes in the way children and their families in the area accessed children's rehabilitation services.

Her son, Mike, now 13, has cerebral palsy and the family had to travel regularly for years to the Ottawa Children's Treatment Centre for therapy.

Whitney is pleased with the services Mike has received. He is now a Grade 8 student, looking forward to high school and very active in sports including sledge hockey and Paralympic downhill skiing.

The opening of One Kids Place in October 2005 has made a big difference for children and their families in the Districts of Muskoka, Nipissing and Parry Sound, she says.

One of the difficulties before the CTC was established was the scarcity of therapists in the region, she says. "With the opening of the CTC, we were able to pull together a critical mass of therapists, all working together," she says.

One Kids Place, as a visible presence, also raised the profile of children's rehabilitation services in the community, Whitney says. "It provides people with one door to access the services

their children need."

Increased provincial funding has helped to build therapy services for children with disabilities and expand services to satellite offices, she says. But additional funding is necessary to expand the range of services of the newest CTC in the province, she says.

There is no psychology and very little psychoeducational assessment locally, she points out. "We have just now hired one recreational therapist who has a huge geographic area to cover."

Children's services are excellent from zero to six years of age but once children reach school age they don't get the

same level of services, she says. It can be a barrier when the same Ministry does not provide services for school children as those provided for younger children.

Funding to decrease the wait list time for treatment at One Kids Place from its current period of about a year is also crucial, Whitney says. "Early assessment and treatment is so important," she says.

The operation of satellite offices in Parry Sound and Huntsville is expensive and more funding is needed to meet that need, she says. "We are geographically challenged in the north and we need adequate funding to meet this challenge."

"We are geographically challenged in the north and we need adequate funding to meet this challenge."

—Leeann Whitney, parent



Eager to learn

Faith Turner participates in one of many enrichment activities offered at John McGivney Children's Centre in Windsor.

Twelve weeks long enough to wait for services: Earle

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— an average of 26 weeks.

Earle notes that early intervention is very important. "It increases the potential for independence, activity and participation," she says.

It has been documented that early intervention influences school success, averts secondary problems like reduced self-esteem, and helps improve family functioning.

OACRS has identified that 12 weeks is a reasonable length of time for children to wait for treatment, says Earle.

"After that, the opportunity is reduced to have as much impact with rehabilitation and services."

Based on the number of children waiting and how long they've been waiting for treatment at each CTC, OACRS has established \$9.4 million is needed to reduce wait times for 3,200 new unique children.

CTCs also need an additional \$11 million in new annualized funding

to ensure that no child receives less CTC service than needed.

"Some CTCs, if not all, have also diminished their level of services for each child in order to reach the children on the wait list," says Earle. For instance, if a child requires two visits a month for a therapy, it may be reduced to one visit, in order to free up the time to see another child, also at a reduced number of visits.

"With the best of intentions to help the wait list, the result is that the optimum achievement of goals is often sacrificed," says Earle. "We're reducing the benefit to the child if we don't provide the level of service required."

A survey of the CTCs revealed that nearly 21,000 clients, almost 50 per cent of the total number served, have been affected by the service reduction.

OACRS is also asking the Ministry of Children and Youth Services (MCYS) to invest \$93

million in one-time capital funding for the CTCs. Earle says that while the request is large, "needs have built over time." CTCs do not receive annual funding increases, so they fall behind over time.

CTCs currently see about 45,000 children. The average amount of therapy per child per therapy type is one hour a month.

"It's not a lot, but there are huge returns for the individuals, for the family, and for the community as a whole," says Earle. "This investment in children and youth can help them reach their potential and have the opportunity to participate in life to the greatest extent possible. It not only improves their quality of life, it reduces the pressures of required services from society as a whole."

"I firmly believe this is wise fiscal management, let alone what a compassionate society should do for its children, especially with its most vulnerable children," she says.



For ongoing coverage of how new funding is being used, visit:

www.oacrs.com

Addressing wait times is crucial, says parent

By Michelle Strutzenberger

Andrew Nelson believes that more annualized funding for Children's Treatment Centres (CTCs) is critical, especially to address wait times.

"Our kids are so important to us," he says. "We can't see them on a waiting list for crucial treatments."

The Nelson family has personal experience with waiting for therapy.

Several years ago Josh Nelson, now 12, was diagnosed with a cancerous brain tumour. Surgeons at Mc-

Master Hospital were able to remove the brain tumour but he was left unable to walk or even lift his head. He also lost his ability to speak.

While he has since received the physical therapy and speech therapy he requires and has made much progress, Nelson describes the wait for the speech therapy in particular as very difficult.

"We didn't get any help because he wasn't a baby or an adult," he says. "Isn't that crazy?"

Josh lost his speech in June, 2003. He didn't see a speech therapist until January, 2004, a wait of over seven months.

"Why the waiting?" Nelson wants to know. He adds that the family felt it was most important to see Josh's speech restored. "We wanted to be able to communicate with him so he wouldn't be frustrated."

In the end, the Nelsons took it upon themselves to try to teach Josh "what we thought was therapy."

'Our daughter wasn't thriving but we couldn't access services needed'

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"So many things depend on them getting the right amount of service at the right time," she says.

While Holte says that her daughter is receiving very good care at Kids Ability, she has personal experience with the impact of waiting.

"It was incredibly painful and frustrating." That's

how Holte describes the time of waiting for rehabilitation therapy for her daughter. "We knew our daughter wasn't thriving but we couldn't access the services she needed." At a year and a half Sydnie was not yet crawling, nor could she move to a sitting position on her own. There were other significant signs of delayed development.

Finally, seven months

after an initial referral, Sydnie could begin seeing therapists at KidsAbility. Months of intensive physiotherapy led to Sydnie walking on her own at the age of three.

Now the Holtes are going through the whole

potential negative impact of the delay.

Holte is so passionate about seeing wait times reduced and service levels raised that she is co-leading a letter-writing campaign. This month she is working hard to mobilize parents

connected to KidsAbility to take part in the campaign, which is to include a presentation to the MPPs of Waterloo, Ontario, as

well as a media blitz.

"Parents of children with special needs must come together and deliver a powerful message to those in the Ontario government who make funding decisions," Holte writes in a letter to parents asking for their involvement. "Providing complete funding for children with special needs must be a top priority on the government's agenda."

'Providing complete funding for children with special needs must be a top priority on the government's agenda.'

—Bobbi Holte, parent

process again as they wait for therapy for their second child, Sam. Twenty months old, Sam has been on a waiting list since August, 2006. "It's just as painful the second time around," says Holte.

She deals constantly with knowing that her son could be helped if he could access services, knowing that he can't access those services until an opening comes up and fearing the

Continued advocacy needed for children: Stephen Lewis

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document and share how clinicians measure change and improvement in the children they treat. "We are all anxious to make sure the funding is making a difference for the children," says Earle. This program is the first phase in a process to ensure optimal outcome measuring.

This past year also saw an exciting OACRS conference, says Earle.

Minister of Children and Youth Services Mary Anne Chambers, with whom OACRS has developed a strong relationship, spoke at the conference, highlighting the need for "more work to be done" for the province's children. Stephen Lewis, former Canadian Ambassador to the United Nations and currently the Secretary General's Special Envoy for HIV/AIDS in Africa,

offered the keynote address. He highlighted the need for continued advocacy to raise children to a higher priority.

"We really appreciate Lewis' support of our centres," says Earle, noting that Lewis has since offered additional support to the CTCs by speaking to the need for additional funding in an OACRS funding request document to MCYS.

EDITORIAL

Now is the time to fulfill the commitment to children with disabilities

In May, 2006, the Ministry of Children and Youth Services invested an additional \$10million in Children's Treatment Centres in Ontario. Now, more than 4,000 children with disabilities, who had been on long wait lists, are able to access the therapy services they need, services that are helping them to reach their potential and ensure success – at school and in everyday life.

But despite this investment, thousands of other children are still waiting for services or are receiving less than they need – less than the average of one hour of service per month.

There remains a serious shortfall in this Government's funding for children's rehabilitation services.

Delays in treatment usually mean lost opportunity: the effectiveness of therapy is more often than not diminished as the child ages. The opportunities for children to enjoy greater independence and increased participation in daily life are threatened.

Children's Treatment Centres across the province are working hard with the resources they have, but now is the time for the Ontario Government to demonstrate its commitment to the future of our children.

Children's Treatment Centres must be funded sufficiently so that no child receives less than adequate services and no child has to wait more than 12 weeks for those services to begin.

In September, 2006, 5,000 children were waiting, an increase of 25% in one year and the wait list continues to grow. In order to reach therapy goals, a staggering 21,000 children receive "diluted" services that are less than they require to succeed.

In order to address these needs, OACRS has submitted a budget request for \$9.4million to reduce wait times to 12 weeks and \$11million to end the dilution of services.

Parents across the province are speaking out to encourage the Ontario Government to increase their investment in these vulnerable children. And Mary Anne Chambers, Minister of Children and Youth Services, has acknowledged that investing in our children will benefit society in the long term, pledging that "Our Government is determined to help kids reach their potential."

Now is the time to step up, on behalf of children with disabilities across Ontario, and fulfill this commitment.



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Funds needed to continue building base of services in North Bay region

By Craig Anderson

Therapy services for children with disabilities in the North Bay region have been steadily strengthened since the inception of One Kids Place in June of 2005, and Judy Sharpe, Executive Director, is hoping new funds will be allocated to allow the centre to develop specialized clinic programs.

With a base of “very skilled” therapists, says Sharpe, the centre has managed to expand services in the past year, establishing satellite sites in Muskoka, Nipissing, Parry Sound, and Huntsville. The children’s treatment centre (CTC), which currently provides therapy services for more than 3,000 families, wants to add augmentative communication and seating and mobility clinics.

“We want to build upon what we’ve been able to create,” says Sharpe, who says that new funds will “expand the range of interventions available and possible.”

Last year’s increase in funding – One Kids Place (OKP) will now receive an additional \$155, 220 annually - helped the centre build upon the treatment system it established in 2005. Sharpe says that the funds were sorely needed as no cohesive CTC, and the strong, therapeutic culture often attached to it, had existed before.

Prior to 2005, therapists worked out of the Children’s Rehab Services Program of

North Bay General Hospital and were funded under the hospital’s envelope.

People in the region are thrilled, she says, with what has been established to date. Yet, due to the paucity of services existing before, and a lack of a base, more momentum for expansion of services is a necessity.

“We want to go forward with an ask,” says Sharpe, “that will bring appropriate dollars that our region has not had access to given an absence of a treatment centre over all these years.”

The centre is looking to continue to target its wait lists, and although significant gains have been made through the established satellite sites - increasing accessibility for parents in more remote areas – “the need is still there.”

“And we can’t pull back from existing services,” says Sharpe.

Service delivery methods, such as the block system, could be strengthened through additional funding support. With the block approach, children receive therapy for months at a time and are then “off block” for a similar period. Sharpe explains that although the block system itself isn’t necessarily a method of ameliorating wait times – blocks are but one service delivery method – new funds would have an impact.

“We could have more treatment in a smaller period of time,” she explains.



Tyler Sonneveld in speech therapy with Jenn Cadotte, Communicative Disorders Assistant at Prism Centre for Audiology and Children’s Rehabilitation in Chatham.

Investments in children today lessen burden in future

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children not being able to receive therapy right in the centre.

“I am very pleased with the [centre] and the services, but very concerned about the trend in therapy,” says Grail. “If we don’t get an increase the trend will be to look at ways of cutting.”

Offering an example, Grail says that the centre currently prioritizes therapy for children with the highest needs. Grail ex-

plains that this approach, which is meant as a way of mitigating the impact of a dilution of services, negatively affects those children with lower needs.

“The [funds] certainly did help with wait times,” says Grail, who has lived in the Chatham area for fourteen years. “It was great and positive, but it just wasn’t enough.”

“The centre and the therapists are doing the best they can, and they are doing a great job, but they

could do so much more.” Grail argues that investments in children today lessen the burden on governments in the future. The Prism Centre, she says, could use an additional six or seven therapists to meet local need.

“The philosophy should be to invest up front,” says Grail, adding that quality therapy now will translate into adults less reliant on government services.

“It could save them ten-fold,” she says.



Sensory stimulation

Kirk Gauthier develops his sensory capabilities with therapist Heidi Haldemann at Children’s Rehabilitation Centre-Algoma in Sault Ste. Marie

Children’s Treatment Centres (CTCs)

<p>Belleville Quinte Children’s Treatment Centre Cavell Building Quinte Healthcare 265 Dundas St. East Belleville, ON K8N 1E2</p>	<p>London Thames Valley Children’s Centre 779 Baseline Road East London, ON N6C 5Y6</p>	<p>Sault Ste. Marie Children’s Rehabilitation Centre - Algoma 74 Johnson Avenue Sault Ste. Marie, ON P6C 2V5</p>
<p>Brantford Lansdowne Children’s Centre 39 Mount Pleasant St. Brantford, ON N3T 1S7</p>	<p>North Bay One Kids Place/La place des enfants 945 Stockdale Road North Bay, ON P1B 9S5</p>	<p>Simcoe York Children’s Treatment Network of Simcoe York Simcoe Resource Centre 165 Ferris Lane Barrie, ON L4M 2Y1</p>
<p>Chatham Prism Centre for Audiology and Children’s Rehabilitation 355 Lark Street Chatham, ON N7L 5B2</p>	<p>Oshawa Grandview Children’s Centre 600 Townline Road South Oshawa, ON L1H 7K6</p>	<p>Sudbury Sudbury Regional Hospital - Children’s Treatment Centre 1204 St. Jerome Street Sudbury, ON P3A 2V9</p>
<p>Halton-Peel Erinoak 2277 South Millway Mississauga, ON L5L 2M5</p>	<p>Ottawa Ottawa Children’s Treatment Centre 2211 Thurston Drive, Ottawa, ON ON K1G 6C9</p>	<p>Thunder Bay George Jeffrey Children’s Centre 507 N. Lillie Street Thunder Bay, ON P7C 4Y8</p>
<p>Hamilton Developmental Paediatrics & Rehabilitation McMaster Children’s Hospital Room 112, Southam Building, Chedoke Site Sanatorium Road Hamilton, ON L8N 3Z5</p>	<p>Peterborough Five Counties Children’s Centre 872 Dutton Road Peterborough, ON K9H 7G1</p>	<p>Toronto Bloorview Kids Rehab 150 Kilgour Road Toronto, ON M4G 1R8</p>
<p>Kingston Child Development Centre Hotel Dieu Hospital 166 Brock Street Kingston, ON K7L 5G2</p>	<p>St. Catharines Niagara Peninsula Children’s Centre 567 Glenridge Avenue St. Catharines, ON L2T 4C2</p>	<p>Waterloo KidsAbility - Centre for Child Development 500 Hallmark Drive Waterloo, ON N2K 3P5</p>
	<p>Sarnia Pathways Health Centre for Children 1240 Murphy Road Sarnia, ON N7S 2Y6</p>	<p>Windsor John McGivney Children’s Centre 3945 Matchette Road Windsor, ON N9C 4C2</p>

