

# OPENING THE DOOR

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*Toronto developmental services agencies, consumers, and the Toronto Region of the Ministry of Community and Social Services are working together to improve the quality of life of adults with developmental disabilities—today and into the future. We are committed to the equitable, strategic and effective use of all available resources in meeting the needs of adults with developmental disabilities and their families.*

## Partner Agencies

Check out [www.dsto.com](http://www.dsto.com) for information about partner agencies and developmental services provided in Toronto.

Addus	416-544-8847
Bob Rumball Centre for the Deaf	416-447-2378
Christian Horizons	416-630-3646
Community Living Toronto	416-968-0650
CORE	416-340-7929
Common Ground Cooperative	416-421-7117
COTA Health	416-785-9230
Family Service Toronto	416-971-6326
Geneva Centre for Autism	416-322-7877
Griffin Centre	416-222-1153
Harmony Place Support Services	416-510-3114
JVS Toronto	416-787-1151
Kerry's Place Autism Services	416-537-2000
L'Arche Toronto Homes Inc.	416-406-2869
Mary Centre	416-630-5533
Meta Centre	416-736-0199
Montage Support Services	416-780-9630
Muki Baum Treatment Centres	416-630-2222
New Leaf	1-888-742-3391
New Visions Toronto	416-868-1493
Operation Springboard	416-913-1301
Participation House Toronto	416-439-3226
Pegasus	416-691-5651
Reena	905-889-6484
The Safehaven Project for Community Living	416-535-8525
St. Vincent de Paul	416-265-2605
Salvation Army Broadview Village	416-425-1052
Surex	416-469-4109
Surrey Place Centre	416-925-5141
Vita	416-749-6234
Woodgreen Community Services	416-469-5211
York Community Services	416-653-5400

*For referrals contact any of the above agencies.*

## Three Families' Experiences in Accessing Services and Funding

By Alice Shaw

Chinese parents are no different from parents of other nationalities. We also want to do our best to assist our children with developmental disabilities to reach their maximum potential as contributing citizens. Getting our children the right kind of services is the key to achieving our goal.

I would like to share the experiences of three adults: Raymond (age 18 ½), Julie (age 22) and May-May (age 44). Their ability levels, health conditions, ages and family situations are all different. However, one characteristic which is common to all three families is that their parents are all immigrants to Canada and English is not their first language. These stories can help share how immigrant families are affected by services and supports.

Raymond was diagnosed with tuberous sclerosis and experienced frequent severe seizure attacks. He requires 24-hour supervision from two people as he weighs over 140 pounds and his mother alone cannot hold him and give him medication at the same time. He has to wear a helmet at all times to protect his head in case he has a seizure. Despite the precautions taken, he still broke his arms and legs.

Raymond was a client of Surrey Place Centre since birth. Surrey Place Centre was very supportive of him. They assigned a Cantonese-speaking staff person to work with him and his family. The worker was the vital link between Raymond and the services in the health, educational and social services system. She helped locate suitable school programs and summer camps. She also arranged for the help of a translator so he could have help applying for Ontario Disability Support Program (ODSP), visiting hospitals, and meeting with teachers. Without pre-arranging for a translator to help, doctor appointments at the hospitals sometimes took a full day. This has put a lot of strain on his parents and older brother as two people had to be with him at all times, including when he came home from school. Both parents have to stay with him every night.

For Raymond and his family, the assistance of a Cantonese-speaking worker as he moves into adulthood would certainly alleviate significant burdens on his family.

The second story is about Julie, who was diagnosed with cerebral palsy with significant developmental delay due to trauma at birth. She learned how to walk at the age of five and still has challenges walking down the stairs. She communicates with gestures, single words and simple sentences. Although she can do some things independently, she needs help taking care of herself. She has to be with an adult at all times. After she left high school two years ago, she started to attend a day program run by Addus, one of the partner agencies. The program starts at 8:30 in the morning and ends at 3:00 in the afternoon from Monday to Friday. Each day, Julie takes part in different activities aimed at improving her life skills.

It was an overwhelming experience for Julie's parents at first because not only did they spend time looking for a suitable and affordable program, they had to arrange transportation to and from the program on their own. Both parents were working full time when Julie first started going to Addus. Hiring someone to take her to the program twice a week would cost \$45 per day three years ago when Julie was in our last year of high school. As of the end of April 2007, Julie's mother decided to quit her job so that she could take her to the program, where she could learn to be more independent. Since she joined the program, she has learned to use buttons and zippers. She is also able to vacuum, wash dishes and prepare lunch with some help.

It would be helpful if an affordable bus service (similar to Wheel-trans) could be offered to people like Julie, who can walk but cannot take the TTC on their own. A more flexible use of Passport funding that included transportation costs may also be an alternative. A web service with full listings of agencies, including their locations, schedules and cost would definitely improve the search process for parents. Setting up a parent/peer-to-peer network to share information would also be helpful as very often people get to know a good program through other parents. Children with disabilities can certainly benefit from continued education after they finish high school.

*Cont'd on page 4...*

## Developmental Services Toronto

### Achievements 2007 / 2008

#### Strengthening the Voice of Consumers

- Created the Consumer Engagement Facilitator role and hired a Facilitator who has engaged in outreach to self-advocates, families and the groups and organizations that support them
- Developed and introduced plain language guidelines for all Council activities
- Completed the development of a workplan for Council which includes the following priorities:
  - Creation of a self-advocacy network
  - Confirmation of a process to identify issues and outcomes of importance to consumers
  - Development of connections with individuals with developmental disabilities and family members from diverse communities
  - Promotion of citizenship through public education
- Discussions between the Council and the Ministry led to the creation of an ODSP User Advisory Group at an ODSP office in North York
- Completed membership renewal process on the Council

#### Enhancing Services and Supports

- New services created / people served:
  - Supported Independent Living = 13 individuals
  - Innovative Residential = 12 individuals
  - Dual Diagnosis units = 10 individuals
  - Facilities = 25 individuals in 2007-08 ( 86 to date)
  - At Risk = 5 individuals
  - Passport = 40 individuals
- Successfully implemented Integrated Response approach including Interim Support component  
Completed sector-wide “refresher” training sessions
- Developed and approved a protocol with Child Welfare Agencies and the Special Needs Team for service data sharing to assist with system planning. The protocol will provide non identifying information about children currently aged 14 who will be leaving child welfare and special needs placements and entering the adult developmental services system.

#### Building A Service System

- Service Provider Committee developed a workplan for the coming year that included the following priorities:
  - Develop an Access / Application Centre model for Toronto based upon Provincial Guidelines and the dsto collaborative approach
  - Coordinate and consolidate data collection and reporting systems within dsto
  - Create an approach to identifying, approving and allocating the resources required to support dsto priorities and activities
- Developed and approved Conflict of Interest Guidelines for dsto groups
- Reviewed Designated Agency role, and clarified accountability for Designated Agencies
- Consolidated oversight responsibility for access through the creation of the Integrated Response and Access Committee which has representation from all dsto access mechanisms
- Strengthened sector communication through:
  - Creating a brand, tag-line and logo for dsto
  - Developing guidelines for the consistent use of the dsto brand and logo
  - Producing two newsletters annually
  - Updating and reprinting dsto brochure on how to access services and supports (Integrated Response)
  - Planning and holding the second annual dsto Information Fair attended by over 400 people

- Strengthened sector information collection and planning by:
  - Reviewing current information collection practices and databases with the goal of consolidating and strengthening both
  - Developing a proposal to engage in neighborhood mapping in order to better identify patterns related to the well-being of adults with developmental disabilities and dsto services and supports
  - Completing the Year 3 Community Plan
- Improved quality across the Partnership through:
  - Completing 6-month review of Integrated Response approach and approving recommendations for strengthening approach
  - Completing 1-year review of the Passport initiative and approving recommendations for strengthening future practice

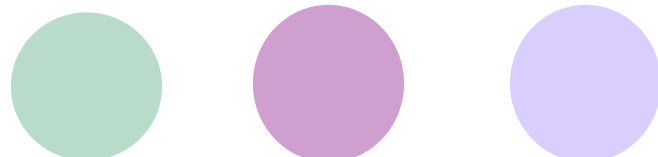
### dsto Council News

The Council devoted its July meeting agenda to a discussion of Bill 77. Council supported the following aspects of the legislation:

- (i) broadening of the definition of “developmental disability” to include both cognitive and adaptive functioning.
- (ii) expanding the ways in which the Minister may fund services for persons with developmental disabilities to provide for greater customizing of services and supports.
- (iii) ensuring greater consistency in the determination of eligibility, processing of requests, and prioritization for services so that individuals and families understand how the access process works, and feel that decisions are made in a fair, consistent, and transparent manner.
- (iv) supporting individuals with developmental disabilities to live in community settings of their choice.

At the same time, Council members also identified some concerns about aspects of the proposed legislation. It therefore had six recommendations:

1. New funding be made available to coincide with the increase in the number of individuals eligible for developmental services given the broadening of the definition of developmental disability.
2. New funding be made available to support the creation and operation of the new application centres.
3. The Ministry develop policy expectations regarding the responsibilities of application centres’ to support those on the waiting list and to develop strategies to reduce the numbers on the lists.
4. The proposed legislation include a review process to be used by individuals, families, or others that have concerns regarding safety and quality of service.
5. The proposed legislation include the description of a fair and impartial process that can be used by individuals and families if they wish to appeal a decision made by an application centre.
6. The Ministry consult on the details of transformation as it develops regulations and policy directives in support of the new Act.



## Accessing Developmental Services for Adults

Developmental Services in Toronto (DSTO) is into its second year of a coordinated approach to processing requests for service for *first time callers* to the adult sector who are:

- 16 years and older,
- Live in Toronto and
- Have a confirmed or suspected developmental disability

### Who do you call?

A call to any one of the 32 partner agencies (listed on the front of the newsletter) provides eligible callers with:

- Information about services and supports available for adults with a developmental disability and their families and
- The offer of an ‘Interim Support’ visit

### What is Interim Support?

Interim Support visits are a short term support that assists individuals and their family with things such as:

- **Information on government programs** (Special Services At Home (SSAH) & Passport funding) and assistance with completing the applications.
- **Help in getting connected to community programs** (like specialized supports & case management) while waiting for longer term services (like residential programs and community participation supports—formerly known as day programs)
- **Assistance in developing a personal plan**

### What is a Lead Agency?

The Interim Support visit ends with a connection being made to one of the 32 partner agencies who will become your ‘Lead Agency’ and will have the following responsibilities:

- **Ensure that you are registered for service**  
A lead agency is required for individuals requesting *residential supports*, *community participation supports* or *case management*. Requests for *specialized supports* (i.e. behavior management/therapy, counselling or person directed planning) *respite* and *crisis* do not require a lead but they can be contacted if assistance is required.
- **Act on your behalf when the requested service or support becomes available**  
The lead agency will contact you when you are being considered for a vacancy while waiting for a residential support, community participation support or case management.
- **Provide you with a point of contact should the individual or family’s circumstances change**
- **Keep the individual and/or family informed by forwarding appropriate communications**

Regardless of whether services are requested, the lead agency will keep you informed about new initiatives and respond to any questions or concerns.

## Resources

### Toronto Network of Specialized Care (TNSC)

Four Community Networks of Specialized Care have been set up throughout the province. They are partnerships of community based organizations that work together to provide a variety of professional services, consultations, training, education and research for individuals with developmental disabilities and mental health issues and/or challenging behaviours.

### Access to the Toronto Network Services:

Anyone needing a specialized response to a complex situation who meets the above criteria can do so through one of the five clinical providers: Centre for Addiction & Mental Health, Dual Diagnosis Program, COTAHealth, Surrey Place Centre and Whitby Mental Health Centre.

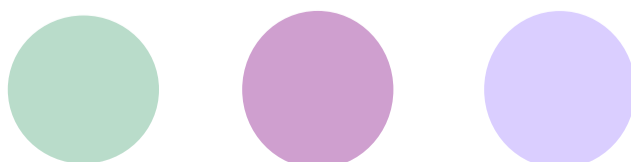
**Clinical Conferencing** is a place where individuals with complex needs and their caregivers can have a coordinated response from a collective expertise of skilled professionals. This can be accessed through your lead agency.

There are **16, time limited, Transitional Treatment Beds** which are focused on setting and achieving specific goals. Referrals for these resources are identified through the **Clinical Conferences**. The agencies operating these are: Griffin Centre, Kerry’s Place Autism Services, and Vita Community Living Services. There are specially trained staff and professionals to carry out treatment plans. The referral source, whether family and/or agency remains involved throughout the treatment period.

**Video Conferencing** is also a network initiative. It is a useful tool which allows people to connect without being in the same room. It is being used for healthcare, counseling and assessment, education and training, professional development, administrative meetings and family visits. A schedule of events and sites can be seen on the network website [www.community-networks.ca](http://www.community-networks.ca) (Registration is required).

The **Mental Health and Justice Coordinator** position was created to assist individuals who are involved in the legal system. Access to this service is through the Griffin Community Support Network - 416-222-1153.

For more information on the Specialized Networks check out the website at [www.community-networks.ca](http://www.community-networks.ca) or contact Sandra Bricker at [sandra.bricker@surreyplace.on.ca](mailto:sandra.bricker@surreyplace.on.ca)



## Paddles Ready . . . Take it Away!

These are the words that Spirit Challenge Dragon Boat teams have learned to respond to in preparation for their participation in the Toronto International Dragon Boat Race Festival (TIDBRF). Since 1999, Spirit Challenge has introduced people with disabilities to the sport of Dragon Boat racing. It provides a thrilling, competitive, adventure based experience to people with intellectual and physical disabilities; promoting physical activity, team spirit, and equal access barrier free inclusion. The partners involved in Spirit Challenge in 2008 included New Visions Toronto, Christian Horizons, Meta Centre, Vita Community Living Services, Spirit of Life, Surrey Place Centre, Kerry's Place, Salvation Army Booth Industries, and the City of Toronto Parks Forestry and Recreation.

Dragon Boat racing is one of the fastest growing sports in the world. It was originated to commemorate the death of Qu Kuan a great poet/philosopher and statesman who after challenging a corrupt regime took his own life. According to legend, he jumped into the Mei Lo River and after an unsuccessful attempt to rescue him local fisherman beat the water with paddles and threw rice wrapped dumplings as a distraction to prevent his body from being eaten by fish. The Chinese consider the annual event important and it is celebrated in 40 countries throughout the world. Dragon Boat Festivals are full of ancient rituals and customs that go back more than 2000 years.

Four Saturdays prior to the race on June 22, 2008 all eight teams, consisting of approximately 160 people, met at Sunnyside Pavilion for on-water practices. Teams were made up equally of paddlers with a disability and volunteers or staff from the organizations involved. Each boat had a drummer, a coxswain (team member responsible for steering the boat) and 16-20 paddlers. On race day, teams headed over to Centre Island to participate in the TIDBRF Spirit Challenge Championship race. Everyone had a great time and we look forward to next year.

The Spirit Challenge Committee would like to thank the Toronto Chinese Business Association, Atlantic Financial, the National Dragon Boat Club and all our wonderful volunteers for their sponsorship and support in making this possible.



## Mark Your Calendars!

**The Fourth Annual Information Fair  
Will be Held May 14, 2009 at the CNIB**

## Families' Experiences, Cont'd

It would be very sad if they had to stay home because of funding and accessibility reasons.

The third story is about May-May who came to Canada a few years ago to join her parents, who are both in their 70's. She is going to a day program called Under the Banyan Tree. The language ability of her parents is very similar to the parents of Raymond as they speak very little English and rely on the assistance of their other sons and daughter to complete the application forms for various kinds of services that May-May needs. The parents are very worried about May-May, who is now 44 years old as they were told that chances of her going into a group home are very slim. They are determined to take care of her themselves for as long as their health permits. They do not know how to access other services, especially respite services.

To assist this family, it would also be useful if a Cantonese-speaking worker could approach May-May's parents and explain to them their daughter's options for long term care. May-May's family needs to know how May-May can be supported as they get older.

Like other families, Chinese families want our family members be the best they can be and to share what they have to offer with their communities. For this to happen, our families need services and supports that are accessible to people who speak different languages so that we can have the same opportunities that other families have. We want our family members who have a disability to be supported as their needs change so that they can participate in Canadian life as citizens.

## Research Examines Crisis Management for People with Special Needs

*Researchers at the Centre for Addiction and Mental Health are studying what happens when people with intellectual disabilities, autism, or Asperger syndrome have major challenges or are in crisis. The perspectives of family members are very important to this research. More than 30 agencies from Toronto, Peel Region and Kingston are completing data collection forms for the study.*

*Anyone interested in learning more about this research or participating in the study can contact Jonathan Weiss at 416-535-8501, extension 7815 or email [Jonathan\\_Weiss@camh.net](mailto:Jonathan_Weiss@camh.net) For more information on research being conducted in dual diagnosis, visit [http://www.camh.net/Care\\_Treatment/Program\\_Descriptions/Mental\\_Health\\_Programs/Dual\\_Diagnosis/](http://www.camh.net/Care_Treatment/Program_Descriptions/Mental_Health_Programs/Dual_Diagnosis/)*

