

FIRST CHOICE NEWS



SSAHPC SINCE 1990, REPRESENTING 29,000 FAMILIES

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SSAHPC publishes OPEN LETTER February 2009

Dear Hon. Minister Madame Meilleur:

The SSAH Provincial Coalition (SSAHPC) was formed in 1990 by a dedicated group of individuals, families and agencies who joined together for strength and support because of growing concerns regarding the need to expand policy and funding for the Special Services at Home program (SSAH).

We want to complement your ministry for Bill 77 which provides an opportunity for families to receive Direct Funding. We see that as a very positive expansion of SSAH. However, we want to emphasize the importance of SSAH which continues to be an essential program for Ontario families.

Despite the success of SSAH and the new opportunities in Bill 77 without additional funds neither will meet the current needs. Families are suffering in many ways with the daily stresses: depressed economy, schools and preschools with limited resources for children with special needs, young people finished high school with nowhere to go, individuals with complex health needs forced into nursing homes, and older families unable to plan for the future.

In November of 2008 columnist Helen Henderson wrote in the Toronto Star "Help Falls Short for Home Based Care; Road to Inclusion is Paved with Good intentions". She reported the following statistics from the ministry:

- 28,600 families using SSAH in 2008
- Wait lists of OVER 1800 families in June 2008
- last funding increase 2 yrs ago, June 2006 was \$12 M
- Total SSAH budget \$98 M



We encourage you to work with the government of Ontario to enhance the funding available to families through SSAH

Sincerely,
Special Services at Home Provincial Coalition ~~~

5 Actions Recommended from our SSAHPC Paper

- KEEP IT SIMPLE—HELP FAMILIES. DON'T HINDER THEM.
- ENSURE SEAMLESS TRANSITIONS—PREVENT DISTRESS, DON'T CAUSE IT.
- PROTECT SSAH AS A CHOICE FOR ADULTS.
- ENSURE APPEAL MECHANISMS GO ABOVE THE DECISION MAKERS.
- INCREASE FUNDING FOR A STRATEGY THAT WORKS.



Thanks to our Contributors

- Brockville&District Assoc. for Community Involvement
- Community Living Ontario
- Kerry's Place
- Ontario Federation for Cerebral Palsy

***We encourage you to keep your MPP informed of your SSAH story. Write/email your MPP. Here's the link for the MPPs in Ontario http://www.ontla.on.ca/web/members/members_current.do?locale=en

***SSAHPC has sent a recent letter to Minister Madeleine Meilleur, Ministry of Community and Social Services requesting the most recent provincial statistics regarding SSAH in the 9 regional offices.



SSAHPC Five Recommendations

1. Build on the strengths of SSAH.
2. Eliminate the deficit based allocation criteria. Replace it with one that emphasizes potential.
3. Make administrative changes to ensure that families Receive payments on time. Streamline the problem of delay in payments to families by allowing families to fax invoices directly to the regional offices.
4. Strengthen the collaboration between MCSS and the Ministry of Health to benefit families by expanding the Enhanced Respite Program to People over 18 years.
5. Continue to listen to families.

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SSAHPC in Toronto

...Toronto SSAH Advisory is about families

BY JANIS JAFFE-WHITE,
SSAHPC MEMBER

For many years, there has been a family advisory group for the Special Services at Home program in Toronto. Known formally as the Toronto Special Services at Home Family Advisory Committee, this group is actually only one of a very small number in Ontario. Unfortunately, not every region in this province has a functioning Special Services at Home advisory group consisting of stakeholders including family members and program staff. While there have been many changes to the Special Services at Home Program since its inception in 1982, one thing has remained unchanged – the belief of families that they can play a meaningful and ongoing role in addressing Special Services at Home-related matters and concerns. To this end, the Toronto Special Services at Home Family Advisory Committee was formed and continues to meet, albeit less frequently (twice yearly) compared the past (at

least four times/year). I personally became involved as a member on the advisory committee back around 2000 and today I co-chair the committee with another parent, John Gyorkos. All meetings are held at the Toronto Regional Office, two hours in length, and typically held in the evening with light refreshments served.

The Toronto Special Services at Home Family Advisory Committee has its own terms of reference which deals with mandate, membership, frequency of meetings, agenda development, etc. These terms have been updated over the years.

Mandate of the advisory committee covers four areas:

- a) To advise Ministry staff on issues relating to the Special Services at Home program in Toronto.
- b) To identify issues related to the operation and policies of the Special Services at Home program and make recommendations to the

Toronto Regional Office.

- c) To facilitate communication between the users of the Special Services at Home program and staff in the Toronto Regional Office.

- d) To share information and discuss issues related to the needs of individuals and their families accessing SSAH funding.

FACTS about the Toronto SSAH advisory Committee

Any family member who is involved in the care of a person currently accessing Special Services funding may be a member of the advisory.

Meetings are open to any family member or legal guardian and generally attended by about a dozen family members, a Special Agreements Officers and the Special Services at Home Program Manager, Toronto Regional Office [TRO] . Meetings may be attended by invited guests who have been asked to act as a resource and

provide a presentation on a topic of interest.

Effectiveness of Advisory Committee

- To be effective, it also means having access Toronto statistics relating to the Special Services at Home program such as number of applications received, number of applications approved, number of appeals, distribution of children vs. adults receiving Special Services funding, etc.
- Minutes are taken at each advisory meeting.
- Committee members are able to offer agenda items through a call to one of the Co-Chairs before the date.
- A standing item on each agenda is "New Business" to allow time if possible for the discussion of other issues.
- Members are always welcome to bring any resource materials to the meetings to share with other members.
- Advisory committee members provide feedback to the TRO that is based on their own personal experiences with SSAH, as well as information shared by other families receiving SSAH.

SSAH Awareness

It is always surprising to find out that there are still so many families who would be eligible for SSAH funding but are unaware the program exists. While the SSAH program has been around for almost 30 years, there are many Toronto families who learn of the program far too late, if at all. Often it is through word-of-mouth with others or by Googling on the Internet that they find out about SSAH. The professionals who diagnose and/or treat their children do not make them aware of this vital program. Service providers give this type of information but not

every family is associated with an agency.

Since mid-August, Toronto families applying for Special Services funding have been placed on a Wait list, a first for the Toronto Region. This has resulted in a great deal more stress for Toronto families who are already struggling.

Helping Families

Members of the advisory committee have reviewed/updated



of TRO letter templates sent to families regarding SSAH to improve understanding and simplify how funding

breakdowns are presented.

Committee members recommended

- always use plain language, avoid acronyms
- give examples to illustrate points being made
- sentences to the point
- contact information always provided
- decisions relating to a family's application are referenced to ministry policies and procedures.
- emphasis placed to inform families via the Special Services at Home correspondence, that a Special Services at Home Family Advisory Committee exists and how to reach those involved.

Many families on the Toronto committee have been members for years and have adult sons/daughters. There is insufficient representation by younger families i.e. those with children and teens with a developmental

and/or physical disability. It is hoped that more young Toronto families will be encouraged to come out to the advisory meetings to have their voices heard.

Advisory Groups in Other Areas

If you live outside Toronto, why not check if your region has an advisory group that meets to address issues relating to the SSAH program?

The Special Services at Home Provincial Coalition website contains a contact information sheet for SSAH Advisory Groups in Ontario. Sometimes the contact person is a parent, while other times it is an individual from the Ministry's Regional Office. Also, it is important to note that different regions have different names for their advisory group, so don't give up if you are having difficulty locating your own group or contact people. Feel free to call the SSAH Provincial Coalition (www.ssahcoalition.ca) if you feel you need help connecting with the advisory group in your area.

If one doesn't exist, why not start up one yourself with other families and your local regional ministry office? Since Special Services at Home advisory groups are mandated, we have found that they can prove to be invaluable at the local level through the use of collaborative practices and positive partnerships. Let us know how it goes!

The scope of the program and the funds allocated to it have expanded over the years.

1994	9,000 families involved
2004	19,000 A twofold increase!
2007	27,000 families using SSAH
2009	29,000 Still growing

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Member Groups of SSAHPC

Agency Groups

Autism Society Ontario
Coalition for Inclusive Education
Community Living Ontario
Down Syndrome Association of Ontario
The Easter Seal Society, Ontario
Extend-a-Family
Family Alliance ON
Individualized Funding Coalition for Ontario
Kerry's Place Autism Services
Muscular Dystrophy Association, Ontario
Ontario Association of Children's Rehabilitation Services
Ontario Federation for Cerebral Palsy
Spina Bifida Hydrocephalus Association ON

Family Groups

Family Support and Resource Network, Chatham-Kent, Windsor
Essex Family Network, Hamilton
Family Network, Family Voice Lanark, Leeds & Grenville Family Network, London Family Network, Peel Family Network, Sarnia-Lambton Family Network, Toronto Family Network and Thunder Bay Family Network.

We meet 2- 3 times a year. We welcome contributions from member groups , families & friends. We want to hear about your experience with SSAH.

Alison Ouellette & Beth French, Co Chairs
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Keep watching our web site for new stats !
www.ssahcoalition.ca

SSAHPC

c/o BDACI

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SSAHPC SINCE 1990, REPRESENTING 29,000 FAMILIES

Keep What Works for 29,000 Families; They deserve the Best !

An SSAH Story from a Young Family

By CHERIE GAGNON



Special Services at Home (SSAH)

funding can be a "win-win" for you and your child. As a mom with two children with special needs, I anticipate the much needed break. My children, on the other hand, enjoy participating in activities with other kids their age.



With a little creativity and planning, you can discover the many opportunities in the community for your child and use SSAH to make that happen. Our son, Nathan, has Autism and loves swimming but can't join a class without supervision. We had a discussion with our local community centre explaining Nathan's needs and what inclusion meant. Happily, they understood our philosophy and we worked together to make a plan that would allow his support

worker to facilitate his involvement.

Our other son, Joshua, with physical disabilities is a home body and prefers low-key activities. His thrill is going to the park with his personal assistant/support worker. Children have inquiring minds and often blurt out questions like, "What's wrong with him?". His support worker is wonderful at explaining Joshua's condition in simple terms but that despite his challenges he is a regular boy. This often opens up friendships for Joshua and children include him in their play. By looking at what "typical" children are doing, you can start thinking of activities for your child and using your SSAH funding to help.

You'd be surprised with a little conversation, education and planning what doors can be opened.

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### OUR BELIEFS

We believe our advocacy efforts in 1990 encouraged the government to increase the SSAH fund and expand SSAH to serve more people; in particular, children with physical disabilities and adults with developmental disabilities. SSAHPC continues to dedicate our efforts to ensure our mission is achieved.

### We believe that:

- SSAH is a vital support.
- SSAH is essential for families.
- SSAH helps people and families to live meaningful lives in the community.
- SSAH can change and grow to respond to individual and family needs.
- People with disabilities and their families have much to contribute about how SSAH could progress.

