

SSAHPC releases Position Paper 2008, “Keep It Simple; Keep It Flexible and Respectful, Keep it Provincial 27,000 Families Deserve the Best ”

January 2008

The SSAH Provincial Coalition believes that *Special Services At Home* is a powerful and vital individualized support for Ontario families. Unfortunately, we are concerned that the Ministry of Community and Social Services Transformation of Developmental Services may result in the loss of many positive features of SSAH.

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 Special Services at Home program (SSAH). The need to address such concerns continues.

Clearly, families like SSAH. Increasing numbers of families rely on

it. The scope of the program and the funds allocated to it have expanded over the years. 1994 -- 9,000 families were involved. 2004 -- 19,000. That's more than a twofold increase! 2007 -- 27,000 families receive SSAH. That is a threefold increase!

The purpose of this position paper is to ensure that the positive features of SSAH survive the Transformation Process. Our emphasis is straightforward –

Keep What Works for 27,000 families. They deserve the best.

Consistently, families praise SSAH. They want it to be a program of first choice, not of last resort.

SSAH is an approach that the Province of Ontario should protect and enhance, not hinder or restrict. The most prudent approach for the future would include the following five actions:

- 1. Keep It Simple – Help Families, Don't Hinder Them.** SSAH should continue as a unique program rather than blend it into broader approaches that add layers of complexity and discontinuity.
- 2. Ensure Seamless Transitions – Prevent Distress, Don't Cause It.** SSAH should remain a program that allocates provincial dollars to ensure portability.
- 3. Protect SSAH As A Choice for Adults.** SSAH should continue to ease the transition from childhood to adulthood for people with intellectual disabilities.
- 4. Ensure Appeal Mechanisms Go Above the Decision Makers.** SSAH should retain appeal mechanisms that go beyond the local level of decision makers.
- 5. Increase Funding for a Strategy that Works.**

SSAHPC has sent this Position Paper 2008 to the MCSS, Minister Madeleine Meilleur to emphasize that SSAH is important to Ontario families.

We encourage you to pass this information on to other families and your M.P.P..

5 Actions from SSAHPC

- 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 DECISIONS MAKERS
- INCREASE FUNDING FOR A STRATEGY THAT WORKS



THANKS TO OUR 2007/08 CONTRIBUTORS

BROCKVILLE AND DISTRICT ASSOC. FOR COMMUNITY INVOLVEMENT

COMMUNITY LIVING ONTARIO

KERRY'S PLACE

ONTARIO FEDERATION FOR CEREBRAL PALSY



SSSAHPC
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

First Choice News

The Actions Explained

1. Keep It Simple – Help Families, Don’t Hinder Them.

In many ways, SSAH is an elegant program. It is relatively simple and straightforward. It avoids a complex bureaucracy. It is quite flexible in terms of how families can use the funds. It builds the capacity of families to manage their resources.

For many families, SSAH is their first involvement in government support programs for their family member. The application process is relatively straightforward. It does not require families to see their sons and daughters as requiring complex interventions. It enables families to build community around their sons and daughters, and involve their sons and daughters in community, with the support of a personal assistant, not a program.

SSAH is a program that, by and large, treats families respectfully and in a dignified way. It does not overwhelm them with complex requirements and responsibilities. It provides the resources that assist families to meet their expectations

of inclusion. Families determine the best ways to use their funds and can respond quickly to changing needs and priorities within the family. **SSAH empowers families. It is person centered. It builds community capacity.**

In the scheme of things, SSAH provides very little funding to families. Families, in turn, leverage that to great advantage. One of the levers that families gain from SSAH is more energy – they do not have to spend their valuable time and energy with complicated applications and bureaucracies. For many families, SSAH allows them to develop a network of support givers who work together in support of the family. Such intimate networks are nurtured by their own dynamics rather than by complex organizations.

2. Ensure Seamless Transitions – Prevent Distress, Don’t Cause It.

Transitions can be very difficult for people who require support if they face the loss of that support. Two transitions are particularly difficult -- childhood to adulthood, and movement within the province. SSAH has

shown how the stress of these transitions can be reduced. Changes to SSAH could reduce the stress even further.

Because SSAH is available to adults with intellectual disabilities, it helps to make a smoother transition. Other changes could make SSAH more portable within the province.

The Transition to Adulthood - When SSAH expanded to support adults with developmental disabilities living at home, it provided a supportive vehicle with the potential to foster seamless transitions into adult life. Families did not have to become involved in different processes and procedures to keep the supports they had. Families might choose to involve themselves and the family members in other types of support services, but they did not have to give up what they have grown to expect and depend on, and have proven to use wisely.

When SSAH expanded to support adults who moved away from their family homes, it again supported smoother transitions to growth experiences and life changes.

Increase Funding for a Strategy that Works

Flexibility and seamless transitions help families and people with disabilities. Artificial silos and discontinuity hurt them. Families and individuals need assistance, not barriers, to plan for the future. Anything that disrupts continuity of support hurts families and individuals. Leaving school and entering adult life is intimidating for many. Also as parents age, the challenges increase.

The Transition to a New Community (Portability) - The second kind of seamless transition that could be supported by SSAH is movement within the province. The freedom to move within the province is important to all citizens, but especially for families with young children. For employment, educational and family reasons, families often have no choice but to move to another community. Although quite flexible, SSAH is not completely portable throughout the province and therefore families face yet another frustrating barrier. Because SSAH funds are provincial funds, it is far easier for families to move from one community to another without fear of losing their allocation. The simplicity of the SSAH

approach could make it far easier for communities to absorb new members who bring their SSAH support allocations with them. Other forms of service support may be far more complex to deal with, but not SSAH. This vital feature must be protected.

3. Protect SSAH As A Choice for Adults.

A seamless transition from childhood to adult support is important. We think SSAH should be a clear and accessible choice for adults whether or not they have received SSAH support as children. Families can ensure their adult sons and daughters who have moved away from home get the support they need, again in a simple and straightforward manner that does not require the intervention of more formal programs. Some adults will also enter into relationships that evolve into new nuclear families. As one partner in such relationships becomes “caregiver” to the other, the support of SSAH can make a vital difference.

4. Ensure Appeal Mechanisms Go Above the Decision Makers.

For families, it is very

important that SSAH remain a program directly operated by MCSS. It has evolved very successfully to meet the needs of individuals and families. As a provincial program it is possible to appeal decisions up all the way to Queen’s Park. There has been relatively steady progress in making SSAH a program that offers consistent choices across the province. An appeals process to the most senior officials in MCSS is a critical safeguard to ensure the variations from community to community enhance family choice rather than limit it.

5. Increase Funding for a Strategy that Works.

In 2005/06, 25,000 families asked for just over \$131 million in SSAH support. In response, \$85.5 million was given out to just over 22,000 families. In 2007, \$95 million is in the Developmental Services budget for 27,000 families.

The demand for SSAH continues to grow and outpace the funding provided. This relatively simple and highly cost effective program should be expanded to support a far better ratio between applications and

A Final Word

We have called for major improvements to SSAH in terms of applications, fairness and equity, appeals and allocations. Those steps are outlined in the “Background” sheet attached to this position paper. We believe those improvements are important. If the program does not survive in its essentials, however, those points are moot.

Families have grown up with SSAH. They have learned much about their sons, daughters and family members through this individualized support. People are encouraged to talk about what they need and hope for, what their gifts are their own choices for the future, and their rights and responsibilities. They set their own personal goals. They often achieve those goals, often in the face of quite different predictions by others. Inclusion has been the framework for many of their achievements. SSAH is the bedrock of support and an essential tool for success for many individuals and families.

[Actions ...continued on pg 4](#)

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Actions ...continued from pg 3

approvals, and a far better match between requests and allocations. In addition, we support an additional allocation to those already receiving SSAH to allow for an increase in wages. We believe this is long overdue, particularly, in light of the government's recent initiative to provide wage increases to employees of transfer payment agencies.

Member 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

We meet 2- 3 times a year.

We welcome contributions from member groups , families & friends. We want to hear about your experience with SSAH.

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Seminar for families in Pembroke

By Noreene Adam, member SSAHPC

An SSAH info session was held in Pembroke Fall 2007. We were pleased to host families with quite a few new folks attending. We were pleased as we are always looking for new families to share ideas and information. We also had a couple of workers attend as well as staff from Community Living Upper Ottawa Valley who help their consumers and families apply for funding. We had two Service Agreement Officers from the Ottawa office-MCSS attend the gathering. We updated everyone re: the revised guidelines. Afterward MCSS staff were available to speak directly with those families who had concerns. Families indicated they were pleased with the information presented. We also had a woman attend and share, along with her worker the many positive changes that have taken place in her life since she started to receive SSAH funding a year ago. Her story had many present ,

including the people from MCSS in tears. She has gone from a life where she was isolated at home , as she had become the primary caregiver for her recently widowed mother, to getting out into her community, learning about how to navigate shopping malls, stores and the library. She has made new friends and now has been offered a paying job for one morning a week at the local library. Her worker spoke about the importance of getting to know her, and of finding out her interests and then building on this information to enable her to become an active participant in her community. She told us about helping to arrange a birthday party shortly after becoming employed by the lady, and there were four people present, all family members and the worker. This fall, she helped arrange another birthday party and there were fourteen people attending, ten of them new friends met in the past year. I was asked to speak about my experiences in hiring workers. I encouraged

those present to really involve the recipient of the funding to take part in the interview process, and to listen closely to the body language and the non verbal messages given in order to find a suitable worker for each individual. I outlined what my expectations as a parent assisting my son to hire someone, are about what a worker can and cannot do in regards to time spent with my son. One of the issues I really pushed was the need for the worker to maintain confidentiality , not only in regards to my son, but also in regards to us , his family. I took this opportunity to impress upon the Ministry people the importance of adequate funding for families to hire well trained and competent people. Families present indicated that they were quite pleased with the information presented, but perhaps most appreciated of all was the opportunity to meet other families with similar concerns. This networking is so important to families.

We're on the Web !
www.ssahcoalition.ca