

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.**

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 centred. 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

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27,000 Families Deserve the Best***

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.

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

***Keep It Simple, Keep It Flexible and Respectful, Keep It Provincial
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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 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.

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.

Keep It Simple. Keep What Works for 27,000 families!

Background

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.

MEMBERS OF SSAHPC

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

Agency-provincial member groups: Autism Society Ontario, Coalition for Inclusive Education, Community Living Ontario, Down Syndrome Society of Ontario, The Easter Seal Society Ontario, Extend A Family, Family Alliance Ontario, Individualized Funding Coalition of Ontario, Ontario Association of Children's Rehabilitation Services, Ontario Federation for Cerebral Palsy, and Spina Bifida Hydrocephalus Association Ontario.

Five SSAH Specific Recommendations and Requirements for Keeping the Program Accessible, Accountable and Visionary

1. Build on the Strengths of SSAH
 - Enshrine it in policy as a first choice program.
 - Enhance the funding levels by 50% immediately to meet the requests received at MCSS.
 - MCSS's own documentation (website) states: "*The Special Services at Home program ... provides funding directly to individuals/families to purchase services and supports that are not already available in the community*".
 - Families have consistently documented the true cost of supporting a family member with disabilities.

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- Families know that there are not appropriate community based resources.
 - Families need increases to allotments so they can meet the true costs of paying, training and maintaining good support workers.
 - Eliminate the \$10, 000 funding cap.
 - Address the imbalance by increasing the proportions of SSAH funding in all new allocations
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.