

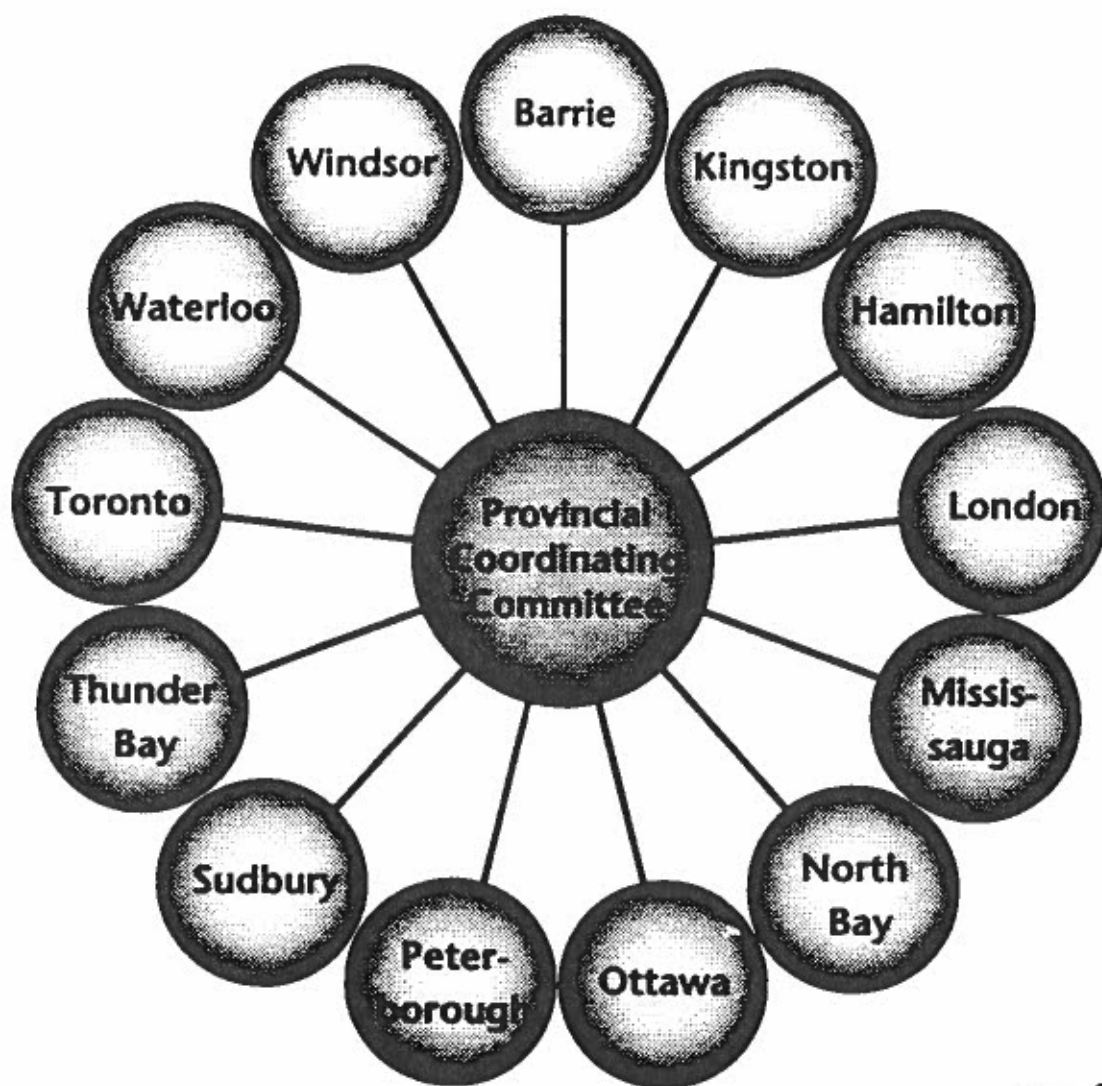
SPECIAL SERVICES AT HOME

**9000 FAMILIES
CAN'T BE WRONG**

**Brief prepared by:
The Special-Services-at-Home Family Alliance**

APRIL-1994

Special-Services-at-Home Family Alliance



Special-Services-at-Home Family Alliance



SPECIAL SERVICES AT HOME: 9000 FAMILIES CAN'T BE WRONG

**Presentation to Brian Low, Director, Developmental Services,
by the Special-Services-at-Home Family Alliance**

EXECUTIVE SUMMARY

To persons with disabilities and their families, the Special Services at Home Program offers opportunities for individualized supports that no other program can match. It is flexible, offering the potential for the development of new options, and it puts control in the hands of the consumers. It offers opportunities for participation in regular community activities. It provides families with supports required to cope with on-going challenges. It has the potential of doing more to prevent institutionalization and other costly interventions than any other program of the Ministry of Community and Social Services.

However, the Ministry of Community and Social Services allocates less than 3% of its Developmental Services budget to this program. Most families cannot obtain the support they need, and many are on waiting lists. MCSS is continuing to favour institutions and service providers in its financial allocations, even though the services they offer are more restrictive, less desired, and less cost-effective than the SSAH program. The SSAH program needs to be recognized for its advantages, to be adequately funded, and to be enhanced.

It is recommended

- 1) That the Minister of Community and Social Services meet with representatives of the SSAH Family Alliance to review SSAH issues
 - 2) That the annual budget for SSAH be increased from \$26M to \$52M this year.
 - 3) That administrative practices and policies need to be reformed to improve equity, accessibility, portability, and scope of the program. These include the recommendations in the final report of the SSAH Reference Group and more.
 - 4) That the Director of Developmental Services designate staff to meet with representatives of the Family Alliance to provide detailed information about financial expenditures and estimates.
 - 5) That the Director of Developmental Services meet with representatives of the Family Alliance in June 94, and September 94 to review progress on SSAH issues.
-

SPECIAL SERVICES AT HOME: 9000 FAMILIES CAN'T BE WRONG

**Presentation to Brian Low,
Director, Developmental Services,
Ministry of Community and Social Services
*Toronto, Ontario, April 12, 1994***

by the
Special-Services-at-Home Family Alliance

*Stan Woronko, Chair
Elizabeth Rose, Coordinator
Gloria Christiansen
Marilyn Dolmage
Jan Burke Gaffney
Myroslaw Tataryn*

Introduction— Who we are

The Special-Services-at-Home Family Alliance is a network of families that include sons, daughters, brothers or sisters, who have a developmental or physical disability and live at home, and who use or wish to use the Special Services at Home (SSAH) Program of the Ministry of Community and Social Services (MCSS). In most cases, members of the Alliance are parents. Our alliance is province-wide, representing 9000 families who currently use Special Services at Home, and many others who require supports but who are not currently receiving any assistance through this program. The Alliance is organized through local committees in each of the thirteen MCSS Area Office jurisdictions, representatives from which sit on a Provincial Coordinating Committee. The Alliance is a new, rapidly growing organization which was formed in November 1993. It believes that Special Services at Home is a good, flexible, individualized family support program but that it is very much underfunded, to the extent that the lack of essential supports is undermining the ability of families to provide care, and is forcing serious crises.

What we do

The Family Alliance is committed to informing families across the province about Special Services at Home, and in particular, about the good and bad administrative practices across Ontario. We promote self-advocacy, and mutual support; we believe in the strength, stability, competence and knowledge that families can offer each other. Families who understand and are experienced with aspects of the SSAH application and appeal processes help others who require assistance. We remind people to hold the government accountable for its programs. We encourage families to apply for what they need, rather than what they have been told they might receive, and to appeal if their needs are not met. We offer assistance and support to families through the appeal process. Currently, the number of appeals is increasing rapidly.

Our values

The Alliance is a network of families of different ages, locations, cultural backgrounds, and experiences, who share common values. These are —

Family We believe that family well-being is essential to individuals and to society. All people need nurturing homes and enduring family relationships. Policies and programs must be designed and delivered in ways that build on family strengths rather than focussing on fixing deficits in individuals. Most MCSS services and programs undermine family unity and cohesiveness, even though they are intended to benefit individuals in the family. *Special Services at Home could be the exception.*

Community We believe that our sons and daughters with disabilities are vital and integral members of our community life, and are valued friends and neighbours. Tolerance is not the issue— membership and belonging are. We want our sons and daughters to be fully included as members of the community, rather than merely seen as clients of programs and services. *Special Services at Home could give us this.*

Control and Self-Determination We have a vital and vested interest in the lives of our children. Therefore we will act in responsible ways to determine what is needed in the way of support and how funds are spent to secure the support we require. We can decide what is in our children's and families' best interest. We can encourage and assist our children to exercise choices and to have control over important factors in their lives. This translates into families having control over

budgets which address individual needs. Special Services at Home is a unique program because, in principle, it supports self-determination. Current administrative practices of some MCSS Area Offices stand in the way of this principle. *SSAH could reinforce this value for all.*

Choice Choice, in the current social services system, is virtually non-existent. Individuals with disabilities and their families are allowed to select from a very narrow range of restricted options. For most, this means serious and unacceptable compromises to fit the program or service. True choice means having the opportunity to seek and to create new options as needed. *Special Services at Home could have the capacity to provide choices for families.*

Special Services at Home has the potential to be a true family support program which supports our values. However, it falls short of this, because MCSS funding favours institutional services which focus on control and on deficits, and which undermine all the above values. MCSS should be more responsive and accountable to families. **MCSS has the lead authority and responsibility to make this Program all it can be - a true family support initiative, which unifies and strengthens families, creates inclusive communities, and empowers families and individuals.**

Do you believe in these values? What do you propose to do to make your Branch more responsive and accountable to families?

The purpose of this meeting

Following our request to meet with the Minister, Hon. Tony Silipo, we were granted this opportunity to meet with Brian Low, the Director of Developmental Services. We accepted, with the following objectives in mind for the present meeting—

1. To re-iterate our demand for a meeting with the Minister, since there are important fundamental issues which need to be addressed: Many families are in desperate need of supports, and the traditional services system cannot respond. The consequences of lack of action on this issue are disastrous for many families, with eventual consequences of costlier 'crisis' interventions.
2. To table our demand for doubling the SSAH funding allocation (i.e. increasing by \$26 million), which is the minimum needed to support families and address the deficiencies in the existing patchwork service system.

3. To table our demand for reform of administrative practices and policies pertinent to the Special Services at Home Program.
4. To set up a working arrangement with Ministry staff for reviewing information on MCSS financial expenditures and estimates.
5. To schedule a follow-up meetings with Brian Low in June and September 1994 to review progress on the above items.

1. Meeting with the Minister

There are a number of fundamental issues which we will discuss with the Minister concerning the existing service delivery system. The MCSS Developmental Services Program funding is hugely biased in favour of institutional supports. Most of the funding, about 97%, supports institutions and transfer payment agencies. Families with high needs are not adequately supported and many families with lower and moderate needs are not supported at all. The promise of MCSS's 1987 publication *Challenges and Opportunities* to deinstitutionalize and reinvest in families and communities has not been met in any significant way.

There are strong families who have provided nurturing care and who are role models for parental support. Over the years they have saved the government millions of dollars by providing all or most of the care and support needs of their sons and daughters themselves. They cannot obtain the supports they need to maintain this approach as they and their children become older. Some have been offered very expensive institutional or group home alternatives which are less desirable than the cheaper self-managed support which they seek, yet they are denied sufficient SSAH or equivalent support.

Reinvestment in families and communities through Special Services at Home is the only answer to fulfilling these promises, being ultimately more cost-effective, and in real terms 'practicing what you preach'. It will also go a long way to saving vulnerable individuals and their families from deteriorating circumstances and victimization due to lack of supports and choices. It is time now to follow enter the next phase of the multi-year plan with a commitment of individualized funding to families and individuals through SSAH.

There is now world-wide recognition of the advantages of giving consumers control and choices, and of turning social services into human services. The old patchwork system of services cannot meet today's and tomorrow's needs. MCSS's *Childrens Services Policy Framework* (April 1993) recognizes that *"there is growing consensus that public policies and social institutions have not kept pace with the changing needs of children and families"*. *Partnerships in Long Term Care* (April 1993) states that *"the current system urgently needs reform to make it more accessible, flexible, efficient, cost-effective and focused on the individual. The consumer must be empowered and control of long-term care services must be vested in the community."*

There is growing evidence and research which support our claim that many of the Alliances recommended reforms would provide for more effective, efficient, and better supports, and produce more positive outcomes for each tax dollar. There have been extensive studies, discussions, meetings and research carried out over the course of the past three to four years. There is no excuse for any more delays; we know what is needed now.

The Minister has not replied to our letters over the last four months; his staff fail to return most of our phone calls. Such a lack of responsiveness by elected officials is unacceptable. We see no choice but to step up pressure for a meeting if we do not have a positive response by the end of this week.

Will you support our endeavours to meet with the Minister, and assist us in this regard?

2. Need for doubling SSAH budget

There is an immediate need to double the funding of the SSAH Program from \$26 million per year to \$52 million. Area Offices report that the average grant is about half of the average amount requested this year. As we write this in early April, we are receiving information that at least one area office has indicated that it has no more SSAH funds for the remaining 11.5 months of the fiscal year, no matter what applications are received from here on!

The shortages are severe in spite of the common practice of families to apply not for what they really need, but to limit their request to what they were told was the maximum they could get. Many are told not to bother to apply for no more than a small number of hours per week of support, even though their needs would justify

much more. Many have been told that, no matter how extreme their needs may be, all grants are subject to a \$10,000 limit. (In fact, the *SSAH Guidelines* specify no limit). Even worse, in some areas, hundreds of families have been told not to apply and have been put on waiting lists (this even denies them their right subsequently to appeal if their application were not granted). Some area offices avoid waiting lists by giving applicants at least a token grant.

While the Ministry of Community and Social Services (MCSS) is claiming to be in favour of de-institutionalization and prevention of institutionalization of persons with developmental disabilities, most of its operational funding for developmental services, by far, is supporting institutions and services which are traditionally segregated and oriented to controlling people rather than offering them options and opportunities for personal growth. The MCSS goal to promote *"strengthening the ability of communities ... to respond effectively to the social and economic needs of families and individuals in ways that reinforce personal dignity and independence"* would be addressed by adequately funding the SSAH program.

SSAH is the most flexible, the most person-centered, and the most cost effective means of providing special supports to persons with disabilities, but it only receives \$26 million per year to serve over 9000 families (average of about \$2800 per year per family). Its budget represents only 2.9% of the Developmental Services operating expenses. By comparison, \$286 million was spent in the past year to provide 514 beds in Schedule 2 institutions in Ontario. The Schedule 2 budget was increased by \$11 million from 92-93 even though the number of beds had decreased since then, from 585 to 512.

The average cost of residence in Schedule 1 and Schedule 2 institutions is \$100,000 per year per person. Families with the most severe needs who are making supreme efforts to avoid institutionalization for their sons and daughters are lucky if they get 10% of that level of support. We are not suggesting that costs be the overriding factor in choosing between program options, but we are saying that SSAH is grossly underfunded in comparison with institutional programs which offer much less in the way of choices and quality of life than family centered supports. A report by J. Lord et al of the Centre for Research and Education in Human Services, found that the level of annual funding provided to families by SSAH ranged from \$600 to \$19,000. For group homes, the range was \$31,390 to \$235,790.

A factor which compounds the funding limitations of SSAH is that in some areas, families do not have any choice of how their SSAH grants are administered. In some

cases, they are forced to use a particular agency as a channel and they lose as much as 35% of their contract to administration fees. In other areas of Ontario, families have the choice of self-administering their funds, thereby avoiding all administrative charges. The Area Offices of MCSS are responsible for these arbitrary and wasteful policies.

Doubling funding for SSAH could be achieved without new dollars, by a cut of 3% in institutional and transfer payment funding (3% of \$868 million). While a 3% cut may present significant difficulties to service providers, it is very small in comparison to the 50% average cutbacks that users of SSAH are experiencing. It is small compared to the differential between institutional per diem rates (up to \$600 per day and even more) and the typical support (\$10 to \$25 per day) that families with the most extreme needs are able to get. The MCSS financial estimates for 93-94 indicate that transfer payments for "Community" Support Services (Adults) were increased by \$85.5 million over the previous year's actual expenditures, while SSAH was held fixed at \$26 million.

Of course, the Ontario government could fund the program by some other reallocations. For example, it recently announced \$52 million would be allocated for summer jobs in Ontario. (This is double the SSAH budget). What it doesn't seem to realize is that families who receive SSAH hire many students, especially during the summer, to serve crucial needs. An opportunity was missed to meet this end by not considering SSAH as an option which could create meaningful new jobs. We wonder how many of the civil service summer jobs are nearly as important and how many are wasteful "make work" projects...

A corollary advantage of funding families directly through SSAH is that service providers will become more responsive to consumers' needs if they have to market and sell their services. They will need to become more accountable to consumers in order to survive as agencies, and consumers will have choices. The service system we have in Ontario has evolved into an unsatisfactory patchwork with many gaps and some low quality services. Putting the funds under the control of the consumer will help to make the whole system more relevant and efficient.

***Will you take immediate steps to re-allocate funds to double the SSAH budget?
Will you allocate funds immediately to assist families who are currently appealing
their SSAH grants, and to those who will be appealing later during the year?***

3. Need for administrative and policy reforms

For more than three years, the Ministry of Community and Social Services has studied and discussed the SSAH program through working groups which involved its own staff, service providers, and consumer representatives. This long and arduous process was supplemented by a major research project carried out by the Centre for Research and Education in Human Services. At least three major documents have resulted: 1) *The Reference Group Report and Recommendations of the SSAH Review*, 2) *Family Directed Support: Diversity, Hopes, Struggles, Dignity*, and 3) *Report on the Administration of Special Services at Home*. These recommendations charted a path for the evolution of SSAH and for reforming some undesirable policies and practices of the Area Offices. We support the intents these recommendations generally, but in some instances we find that they do not go far enough. We note that the recommended implementation for the first phase is already behind schedule. We will exert a lot of pressure if we do not see rapid progress in the months ahead. We believe that the facts are in and the issues have been extensively studied. There is no excuse for further delays.

What exactly are your plans concerning the Reference Group recommendations? Will you proceed to implement these recommendations according to the proposed schedule?

We wish to draw particular attention to the following issues:

a) SSAH is considered to be a program of last resort. We disagree completely with this. Families should not be forced to use existing services when they consider those services to be inappropriate for their sons and daughters. This policy opposes the creation of options and opportunities for choices. It perpetuates systems which are unresponsive to consumer preferences. Consumers need to have more choices over the kinds of supports and services that they access. The focus of SSAH should be changed so that it reflects the priorities of families rather than the service system.

What justification do you see for forcing consumers to use services which they consider to be inappropriate? Will you change your policy to allow SSAH to be an option of first resort?

b) SSAH contracts are not portable in Ontario. The province is divided into 13 areas that do not allow border crossing with SSAH contracts. Families who move are subjected to unnecessary and unjustifiable hardships, ranging from temporary to

permanent loss of funding. It is totally unacceptable to create such barriers to critically needed supports. MCSS could easily allow the funds to be portable through any one of a variety of simple accounting procedures.

Will you address this artificial problem immediately and implement a solution?

c) SSAH contracts are not annualized, even in cases where the needs are clearly permanent. As the end of their contract approaches, families have no idea whether their next SSAH application will be successful. In some areas, it is even worse, as SSAH contracts are awarded for periods of six months at most. On the other hand, most funding provided to institutions and service agencies is annualized program funding. Again, the institutional option is favoured.

Why are families denied the security they need to plan and implement some stability in their lives? Will you implement practices to assure funding continuity where there is an obvious on-going long-term need?

d) SSAH should be extended to adults with developmental disabilities who do not live with their family, but who, with their family's support, want to have a person-centered support system. Currently, there is no funding mechanism for those who need a significant amount of support but who want to exercise choices concerning the kind of supports, the people they live with, and where they live. Many parents now want this option for their sons and daughters because they find typical institutional settings (including some group homes) to be too restrictive.

Will you make it possible for adults with developmental disabilities to receive funding for the supports they need through the SSAH program?

e) Expenses for travel, advertising, professional services, etc... are arbitrarily denied under SSAH. Again, we find discrimination against families using SSAH in that programs operated by institutions and service agencies are not subject to these restrictions. Recognized needs should be eligible for funding regardless of their category.

Will you take steps to remove the restrictions on funding out-of-pocket expenses and professional services under SSAH?

f) Families should have the choice of agencies to administer their contracts, including the possibility of self-administration. Some area offices already offer this choice, but others do not. The choice would make it possible for parents to get the best value for their contract dollars.

Will you implement a policy that will give users of SSAH the right to choose the administrative arrangements for their contract?

4. Need for financial information

Inspection of the financial estimates of MCSS raises many questions about funding of institutions and institutional services versus funding of the SSAH alternative. In some cases, institutional budgets have been increasing, even beyond the levels of previous years' expenditures, by large amounts. This is contrary to our expectations of a policy that is supposed to support community alternatives and consumer choices.

We request that you designate a staff person to be charged with the task of meeting with our representatives to supply additional information about the program allocations. MCSS should provide this service to us to fulfill its primary accountability to consumers.

We also need current data on the aggregate SSAH funding requested and the corresponding level of funding granted, for each of the 13 Areas.

Will you make arrangements for supplying us information on financial expenditures and estimates?

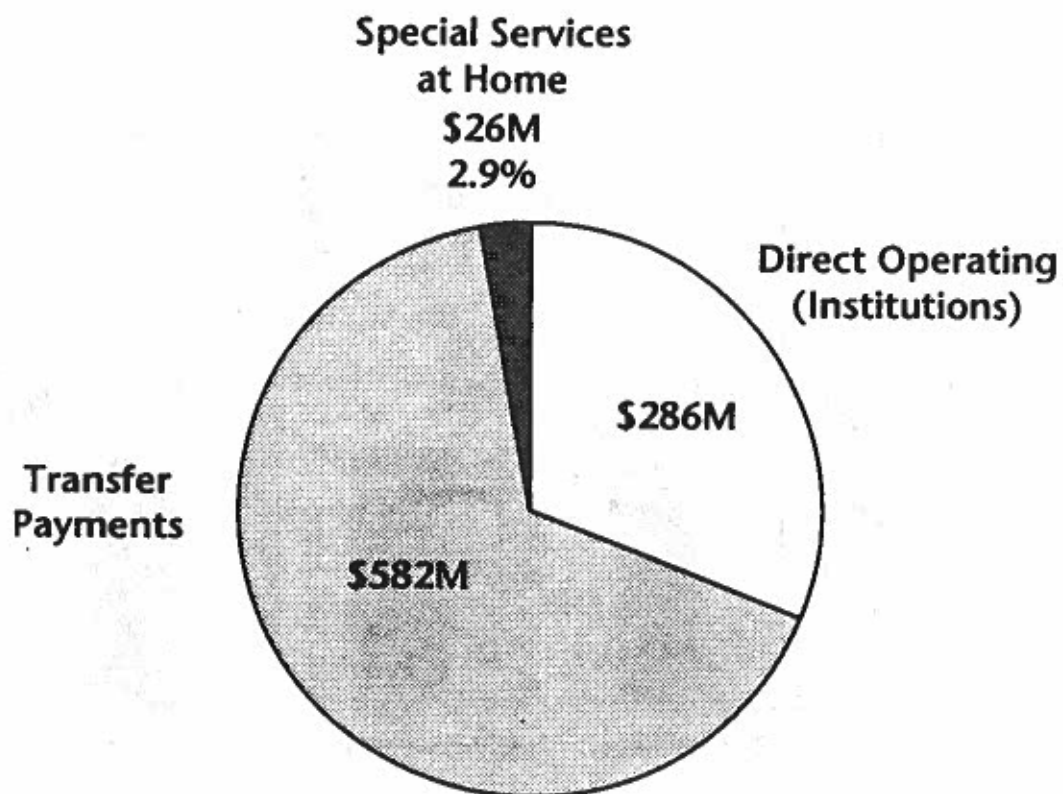
Will you supply data on the total SSAH funds requested vs. approved, for every Area Office?

5. Summary and conclusions

- We want a meeting with the Minister of Community and Social Services to discuss issues related to the Special Services at Home Program. We will exert increasing pressure until we are granted this opportunity.
- We have made you aware of the necessity of at least doubling the funding of the SSAH program.
- We have made you aware of needed administrative and policy reforms, especially with regard to allowing SSAH to be program of first resort, to making SSAH contracts portable, and to allowing annualized contracts. We will be looking for tangible progress from your administration in the coming months.
- We have requested access to financial information through consultation with designated staff. The families that we represent have the right to know how their tax dollars are being spent.
- Finally, we want to schedule follow-up meetings in June and in September to track progress on the issues that we have raised here and on the implementation of Future Directions recommendations.

We believe that cooperatively we can work together to make the Ministry's best program even better.

DEVELOPMENTAL SERVICES Operating Expenses

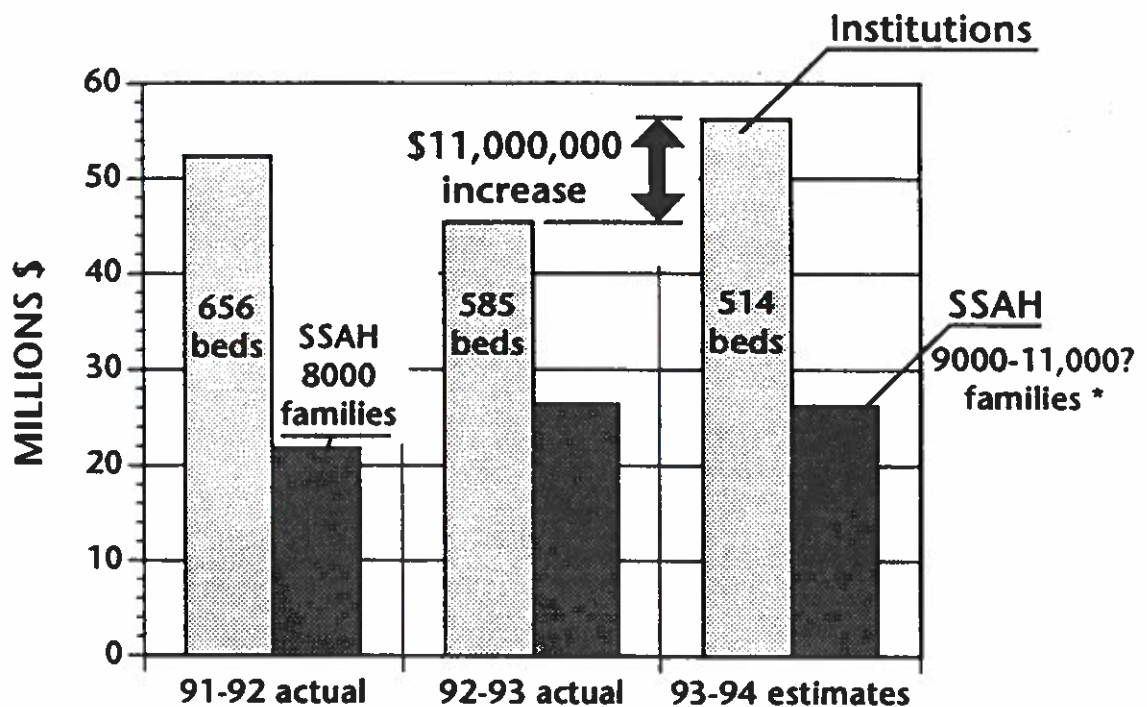


Special-Services-at-Home Family Alliance



Source: 93-94 Estimates.

Budget for Schedule-2 Institutions vs. Special-Services at Home



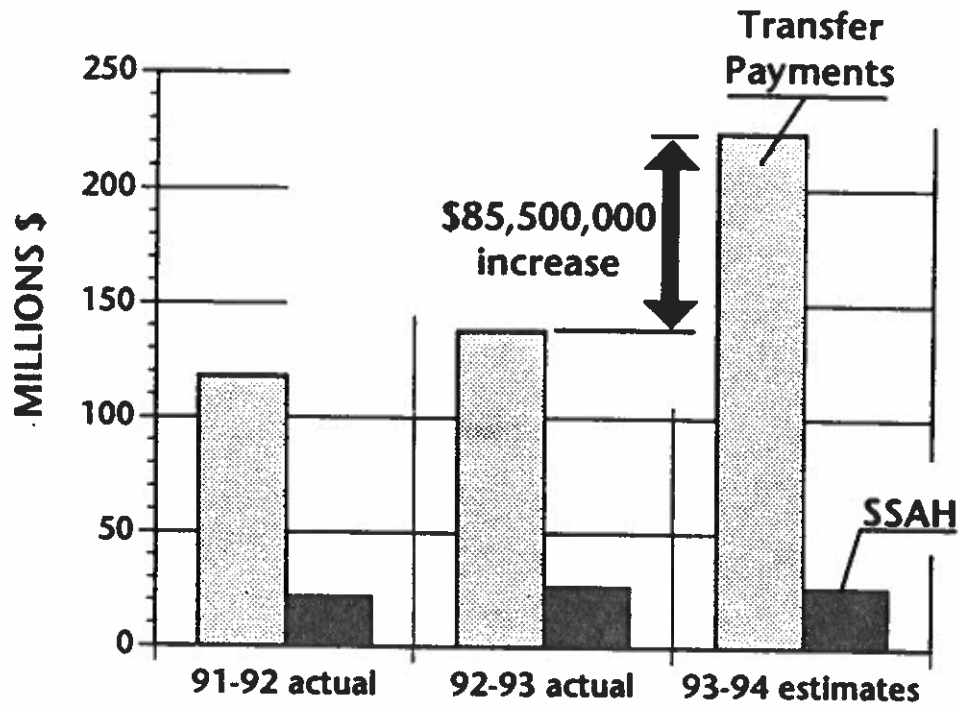
Special-Services-at-Home Family Alliance



Budget for Schedule 2 facilities increases while number of beds decreases, and budget for Special-Services at Home levels off while number of families applying for, or using the SSAH program, increases. Source: 93-94 estimates.

* Hundreds (perhaps thousands?) of families put on SSAH waiting lists and told not to apply.

Transfer Payments for "Community" Support Services / Adults vs Special Services at Home



Special-Services-at-Home Family Alliance



93-94 budget for "Community" Support Services/ Adult increased \$85.5M over previous year's actual, and \$55M over previous year's estimates, while SSAH held steady. Source: 93-94 estimates.

