

**FAMILIES DO IT BETTER —
better supports for special needs
and a better deal for taxpayers**

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Special-Services-at-Home Family Alliance

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YOU BE THE JUDGE!

This is how the Ministry of Community and Social Services
runs the Developmental Services program.

Do you think it is doing a good job? Do you think it is fair?

INSTITUTIONS AND SERVICE AGENCIES		FAMILIES (Special Services at Home)	
ANNUAL BUDGET	\$868 million 	\$26 million 	
NUMBER OF PERSONS SERVED	30,000 	10,000 	
AVERAGE FUNDING PER PERSON	\$29,000 	\$2,600 	
HIGHEST FUNDING PER PERSON	\$235,000 	\$19,000 	
QUALITY OF PROGRAM	"gaps and overlaps in services" ⁶ "dehumanizing institutions" ⁷ "The children died through lack of medical treatment..." ⁸	"Three mixed stakeholder groups agreed ... an excellent fit with the stated purpose and hoped-for outcomes" ⁵	
MINISTRY POLICIES	<ul style="list-style-type: none"> Program of <i>first</i> resort. Funding is annualized, i.e. automatically renewed every year. 	<ul style="list-style-type: none"> Program of <i>last</i> resort. Zero base funding. <p>Need to reapply every 6 months or every year.</p>	
SOURCES	1 Ontario Government Estimates 1993-94 2 Toronto Star, July 1, 1994, p. A10 3 Developmental Services Branch, MCSS 4 Lord, McGowen, and Ochocka (1993), p. 114 5 Lord, McGowen, and Ochocka (1993), p. 122 6 Restructuring Framework Document, June 1994, Min. Community and Social Services 7 Brochure, Canadian Association for Community Living 8 Comments on Christopher Robin Inquiry, People First of Ontario 9 SSAH Guidelines, Ministry of Community and Social Services		

Summary

Some people with disabilities and their families need special supports to deal with demanding challenges in their lives. The cost of meeting their needs through the traditional social service system is high, yet existing services have serious shortcomings. In Ontario, the Ministry of Community and Social Services spends more than \$110,000 per person per year, on average, to keep people in institutions which are generally considered to be dehumanizing. Within its developmental services program, it spends an average of \$29,000 a year per person for services for 30,000 people, but many of these services are not effectively addressing individual needs or achieving any significant community involvement.

On the other hand, funding provided directly to persons with special needs is very cost-effective and can be applied directly to address individual needs and to increase community involvement. Individualized funding empowers consumers, and offers flexibility and choice. It can capitalize on the high degree of personal commitment of people with disabilities, their families, and their personal advocates.

The concept of individualized funding has been very successfully demonstrated by the Ontario Ministry of Community and Social Services with the Special Services at Home (SSAH) program which has existed since 1983. The program has been very effective even though the average grant for the 10,000 families using the program is only \$2,600 per year. Most of the money is used to create jobs, with almost no overhead, as families use these funds to hire support workers, often students. But the Ministry of Community and Social Services treats SSAH as a program of last resort and forces people to use existing services whether they are effective or not, and regardless of the extra cost.

The SSAH program needs to be recognized as a first-choice option and its funding needs to be doubled in order to address current needs. This program currently represents only 3% (\$29 million) of the Developmental Services budget. The other 97% (\$868 million) goes to institutions and service agencies. Expanding the SSAH program will not only give persons with disabilities more control over their own lives, but it will also make service providers more responsive and more efficient as market forces come into play. Through Special Services at Home, both consumers and taxpayers win.

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Introduction

This report was prepared by the *Special-Services-at-Home Family Alliance* for presentation to the Hon. Tony Silipo, Minister of Community and Social Services (MCSS) of Ontario, at a meeting on July 7, 1994.

The Special-Services-at-Home Family Alliance met with Brian Low, Director of the Developmental Services Branch, MCSS, on April 12, 1994, and presented him with a brief entitled *9000 Families Can't Be Wrong*. This brief summarized the issues that surround the critical lack of supports to families in Ontario. A petition was presented to the Minister in the Ontario Legislature on June 8, 1994. The petition, signed by over 2000 people, asked for a significant increase of funding for the Special Services at Home program.

The reader is referred to *Appendix A* for information about the *Special-Services-at-Home Family Alliance*, and to *Appendix B* for a description of the *Special Services at Home Program*.

A statement of the problem

— Families in crisis

Many families are in crisis in Ontario because they have not received the supports they need. They have struggled for years to deal with special needs related to disability— needs for special care, education, training, supervision, and respite, as well as the need to reform society so that it accepts and includes their sons or daughters. Families have made extraordinary efforts for decades, only to find that the required effort is unsustainable as they get older in the face of relentless demands on their time and energy. Many break down at some point and agree under duress to have their sons and daughters placed under undesirable and costly institutional care. Others remain prisoners of circumstances for the rest of their lives, until they die or are no longer physically able to manage — again with the outcome of institutional placement.

The Ministry of Community and Social Services (MCSS) is failing to provide vital supports to many thousands of persons with disabilities and their families. Though the

Developmental Services program is funded at \$868 million per year, it has serious shortcomings. Thousands of people receive little or no support. Many people still live in institutions which are felt to be dehumanizing environments. The Ministry, through its funding priorities, perpetuates a service delivery system which remains oriented to old fashioned segregated services (such as sheltered workshops, and segregated day programs) which are largely ineffective for meeting individual needs, and achieving community involvement. Many people got locked into these services at a time when such services were thought to be progressive.

— Service gaps, lack of accountability, and high costs

Today many families strongly reject the old approaches and want new options which are not widely available in the service system.

Some families are even taking their sons/daughters out of group homes, even though one of the outcomes is that they are left without any services at all. The system is not accountable to them. The Ministry of Community and Social Services prefers to continue funding these group homes rather than to fund the individual needs of these families.

In its *Restructuring Framework Document* (1994), the Ministry states "Social services consumers consistently identify the following shortcomings: gaps and overlaps in services, ... the delivery of some services that do not meet their client needs. Service systems must include the involvement of consumers, and be responsive to the needs of consumers." The Ministry is ultimately responsible for these shortcomings because it persists in funding services which are unresponsive to consumers.

The cost of the Ministry's unsatisfactory service system is high. The Ministry of Community and Social Services spends more than \$110,000 a year on average to keep a person in an institution. On the whole, it spends an average of \$29,000 a year per person for existing services. These figures are derived from Ontario government estimates which indicate that the institutional operating costs are \$286 million/year, and that the Developmental Services budget is \$868 million/year. The number of individuals served in each category is 2,571 and 30,000, respectively, according to the Ministerial announcement of June 30, 1994.

Some of the avoidable costs are shifted to the Ministry of Health to add to the burden of high health care costs. It is a broadly established practice of the Ministry of

Community and Social Services to refuse cost-effective individual supports to families because these families can access placements at such as Bloorview Children's Hospital (\$600/day), and psychiatric hospitals. This is an example of the application of the principle of *last resort*. At a meeting with Family Alliance representatives on June 21, 1994, Brian Low, Director of the Developmental Services Branch, confirmed that the Ministry knowingly prefers to press people to use existing services rather than funding the individual needs of these families, even if the services are not deemed appropriate by the consumers, and even if the services cost more. No particular rationale was given for this policy.

— Ministry treats the best program as the program of last resort

The Special Services at Home (SSAH) program, the program of last resort, has existed since 1983, and has been demonstrated to be highly successful and cost-effective. It receives only 3% of the Developmental Services budget. SSAH has grown over the years, but, in dollar terms, its growth has been minuscule compared to the growth of the service system. But most critically, SSAH has not kept pace with the growth in demand.

The increase of \$3 million in the SSAH budget announced by the Minister Tony Silipo on June 30th is far from sufficient to meet existing needs. This increase represents an average increase of 69 cents a day in support funding for the 12,000 families who are accessing SSAH (or trying to access SSAH). We estimate that over 10,000 are using SSAH this year, and about 2,000 more are on waiting lists.

The average funding for families has actually decreased. Last year, the \$26 million budget supported 10,000 families for an average of \$2600. This year, despite the increase to \$29 million, the average per family has fallen to about \$2400 because the number of families has increased to 12,000. The \$3 million increase is minuscule compared to the \$868 million allocated to the service system for 30,000 clients.

The Special Services at Home Program offers advantages which are unmatched by other components of the Developmental Services program: it is flexible; it can readily address individual needs; it is readily applied to community involvement; it capitalizes on family commitment; and it empowers consumers to have control over their lives. It enforces direct accountability to consumers through their purchasing power. It gives consumers the option of shopping around for services and paying for those that are appropriate. It makes service providers more responsive as their financial viability becomes more closely tied to consumer satisfaction.

— Current practices are poor value for taxpayers' dollars

The taxpayers of Ontario will be pleased to know that the SSAH also happens to be the least expensive and the most cost-effective program. The average funding per person in the service system is \$29,000 per year, which is more than 11 times higher than the average SSAH grant of \$2,600 per year (1993/1994). While the per capita cost of the SSAH program will rise as the program is broadened to address gaps in services, SSAH will still be significantly less expensive. SSAH has less overhead (accommodation, food, clothing, administration, etc.), it can be tailored to provide the exact level of support needed exactly when it is needed (no more, no less), and it capitalizes on the commitment of family members who freely contribute their own time and effort.

— Ministry of Community and Social Services unwilling to act

Over the last four years, the Special Services at Home Program has been intensively reviewed by task forces and a special Reference Group which involved consumer representatives, MCSS and Ministry of Health staff, and service agency representatives. This effort was supported by extensive independent research on the SSAH program carried out by Lord, McGeown, and Ochocka (1993). The Reference Group's report (1993) recognizes the value of the SSAH program and recommends a variety of improvements with timelines ranging from immediate to long term.

The Ministry of Community and Social Services has been showing reluctance to implement these recommendations. The implementation of the first phase of recommendations, which should have started by April 1994 is already behind schedule, with prospects of ever increasing delays for the subsequent phases. Some minor improvements are apparently on the way, but some important recommendations are being set aside — the word from the Developmental Services Branch is that its decisions to accept or reject the Reference Group's recommendations are non-negotiable.

Most of the recommendations of the SSAH Family Alliance are being ignored. Representatives of the Family Alliance met with Brian Low, the Director of the Developmental Services Branch on April 12, 1994 and presented him with a set of recommendations in a brief — *9000 Families Can't Be Wrong*. At the scheduled follow-up meeting on June 21 to discuss the Ministry's response, we received no response to the issues. We were told about processes involving more study, more discussion, and more time, but not about any specific decisions or timelines.

In response to a renewed request for a response to the issues, Brian Low left an 8 minute message on our voice mail at 11:30 p.m. on June 29th. The response included the following— a refusal to support doubling of the SSAH budget, a refusal to allocate funds immediately to support families in crisis, a refusal to support SSAH as a first-choice option, a refusal to deal immediately with the need for portability of support funding, and a refusal to extend the program to adults not living with their parents.

On June 2, 1994, the Family Alliance wrote to request the opportunity to make presentations to the Program Management Committee and to the Deputy Minister's Management Committee. No replies have been received as of July 5.

It is time for the Ministry of Community and Social Services to listen to families, and to start seriously supporting the successful SSAH program as a first-choice option.

The Ministry is at a crossroads — it must choose between two main options:

- 1) perpetuating an inefficient and unresponsive service system, or
- 2) implementing evolutionary changes which are clearly better for consumers and better for taxpayers.

PROPOSED SOLUTIONS

1. The budget for Special Services at Home needs to be doubled

— The current budget

In the 1993-1994 fiscal year, the SSAH program had a budget of \$26 million. This figure is based on the original allocation of \$26 million, plus a \$2 million increase announced in November 1993, less \$2 million which was not actually spent on SSAH but on "Special Needs, Phase 1", which is funding for institution and agency services. The net available to families may have been closer to \$20 or 22 million, because the Ministry allows service agencies to administer contracts with administration fees as high as 40%. The Ministry of Community and Social Services does not know how much is lost to administration fees. According to Brian Low, this is not a matter of concern because the Ministry does not disapprove if SSAH administration fees are used by some agencies to subsidize other services.

— Inadequate funding

To assess the level of unsatisfied requests for support, the Family Alliance asked the Ministry of Community and Social Services for data concerning the requested level of funding compared to the granted level, the number of people on waiting lists and the total demand for funds represented by the waiting lists, and the total demand for funds represented by formal appeals. We found out that the Ministry is in no position to assess the actual needs of families because it does not keep track of these figures. In fact, no attempt is made to determine the needs of people who are on waiting lists.

Even if the data were available, they would still be misleading because many families do not apply for what they need, but follow the instructions of some Ministry staff who tell them to apply for lower amounts because of shortage of funds.

Our experience is consistent with the findings of Lord, McGeown, and Ochocka (1993) (p.126) who state that "... Some area offices have effective documentation systems, others are buried in paper, others have almost no documentation. Overall it is fair to say that the information management system is extremely poor... Accountability would enable SSAH as an individualized funding program to begin to use its learnings and information as a base for informing and influencing other aspects of the human service system. It is perhaps no wonder that the SSAH program has had almost no impact on other planning approaches in the system when the documentation is so poorly developed."

Thus we have no choice but to estimate needs with partial data, extrapolation, and some subjective assessment. We do not claim high accuracy, but we are confident that our estimate is of the right order of magnitude— i.e., the need is about twice as large as the 1993-94 funding.

There are many objective indicators of need for higher SSAH funding. Here are some which we have documented:

- A Mississauga Area Office announcement on April 15, 1994 (just 15 days into the new fiscal year): "Over the past year there has been a dramatic increase in requests for funding under this program. Unfortunately, the available funding has not been able to keep pace with this growth. At this point, we have committed all of our resources for the 1994/1995 fiscal year. Therefore, I regret to advise you that at this time we are not able to process your application(s). Your request for Special Services at Home funding has

been placed on our waiting list." We have been informed that applications for new families after Dec. 1, 1993 have been put on a waiting list.

- In the Hamilton area, all contracts have been cut by 50%. There were 197 families on waiting lists as of March 1994.
- The Peterborough area reported 141 families on a waiting list in April 1994. Last year, all families using SSAH were asked to voluntarily reduce the size of their contracts to fund new applications.
- Some special agreements officers misinform applicants, telling them that there is a limit to the funding they can apply for. In some cases, the "limit" is some arbitrary number of hours of support (such as "6 hours per week"), or the so-called "\$10,000 limit". (The reader is encouraged to check the official *SSAH Guidelines* which do not mention any limit). The Windsor and Barrie area offices were recently reported to be guilty of this practice, but they are not the only ones.
- In April 1994, the Barrie Area Office reported that the applications received amounted to more than \$1 million over the expected allocation. Some families had been called by their special agreement officers in February and asked to reduce their requests. Later, it was reported that there were about 50 formal appeals of SSAH decisions (up from 2 (?) last year). It was reported that the budget for 1994/1995 was fully committed as of June 1994.
- The Kingston area had no waiting list as of April 1994, but many of the contracts are small (about \$500 per year).
- In some cases, families have fewer hours of support than stated in their contracts. Some have been told by Special Agreements Officers that they will only get funded for worker salaries up to a certain level, such as \$8 per hour. Many cannot find qualified workers for such salaries, and have to hire workers at a higher salary for fewer hours. We know of cases where the number of hours purchased is only half the number of hours in the contract.
- There is a growing backlog of formal appeals, in spite of the fact that many families are not informed that they have the right to appeal. Many families

who are using the appeal process report that the Ministry is not responding within 20 working days as stipulated in the SSAH Guidelines. While long delays were common even in previous years, the situation appears to be getting worse. Parents complain that the staff in Barrie Area Office rarely return phone calls about their appeals. Leanne Leitch, of Midland, who appealed to the Assistant Deputy Minister level on May 10 reports that she has called the office (calls for Sue Herbert and Barbara Cooper) about 25 times since June 20th with no calls returned. A response to the appeal is overdue.

- Most formal appeals are rejected, and the main reason for rejection is lack of funds. The Ministry is apparently trying to save face by referring families to non-existent services in their communities — services which are totally inappropriate or services with long waiting lists. Parents who have received such rejections are left without support and are extremely insulted by the response.
- Many families report lack of supports to us. Some have very high long term needs but almost no support. Some of the needs, such as for supporting a son or daughter in a separate residence under the parents' management, are categorically excluded from SSAH, but have been recommended for inclusion by the SSAH Reference Group. Others need vocational training for their son or daughter but are rejected from all sides. Vocational Rehabilitation Services refuses on the grounds that the son/daughter is too hard to serve, while SSAH categorically excludes supports for vocational services. These are examples of service gaps which are a direct result of short-sighted MCSS policies. These gaps could be immediately addressed through SSAH.

— Estimate of funding requirements

As explained at the beginning of this section, we have no choice but to arrive at an estimate of funding requirements through extrapolation of sparse data. As in the practice of polling, we assume that the data we have are representative of the whole ensemble. This is a reasonable assumption because we have no reason to believe that the Ministry does not attempt to divide its funding equitably between its 13 Area Offices across the province, based on the population and the historical level of demand in each area.

We start with the \$1 million shortfall reported by the Barrie Area Office. In 1993/1994, the number of persons served by the Barrie office was 750 out of a total of 9966 for Ontario. We can estimate the provincial shortfall by assuming that it will be in proportion to the population served. Thus the provincial shortfall for 9966 persons is

$$\$1 \text{ million} \times 9966/750 = \$13.3 \text{ million.}$$

Now we will try to estimate the number of people on waiting lists. If we add the numbers from the Hamilton area (197) and the Peterborough area (141), and divide them by the sum of the number of people served in those areas (604 and 866, respectively) we have

$$(197+141)/(604+866) = 338/1470 = .23 = 23\%.$$

Thus, the proportion on waiting lists is 23% of the number of people who receive support. We do not know how many families received SSAH funding this year, so we round off last year's figure of 9966, to 10,000 families. We also round off our estimate of the proportion on waiting lists to 20%. Thus we estimate that 2000 families are on waiting lists. This is consistent with the growth in number of persons served from 1992/1993 to 1993/1994, i.e. from 8,020 to 9,966, an increase of 1,946 persons.

We assume that, on the average, the people on waiting lists have the same level of need as those who received SSAH funding. The total funding requirement is then 20% higher than the sum of the original allocation of \$26 million plus the shortfall of \$13.3 million, or

$$(\$26 \text{ million} + \$13.3 \text{ million}) \times 1.20 = \$47.2 \text{ million.}$$

We still have to add the requirement to broaden SSAH to address service gaps, and to compensate for the many applications that were lower than actual needs because families were told to apply within arbitrary limits (The implication being that your contract will be refused "if you apply for too much"). We note that we still regularly encounter families who are eligible for the program but who did not know that the program exists. Also, some of the contracts need to be increased to afford realistic and fair wages. To cover all these requirements, we (very conservatively) add 10% to \$47.2 million and reach \$51.9 million. The 1993/1994 allocation was \$26,000,000, so our rounded-off estimate of the requirement is double, or \$52 million (Figure 1). If "Special Needs - Phase 1" is included at the same level as last year, the SSAH budget as reported in the official government *Estimates* should be \$2 million higher, or \$54 million.

\$23 MILLION MORE NEEDED FOR SPECIAL SERVICES AT HOME

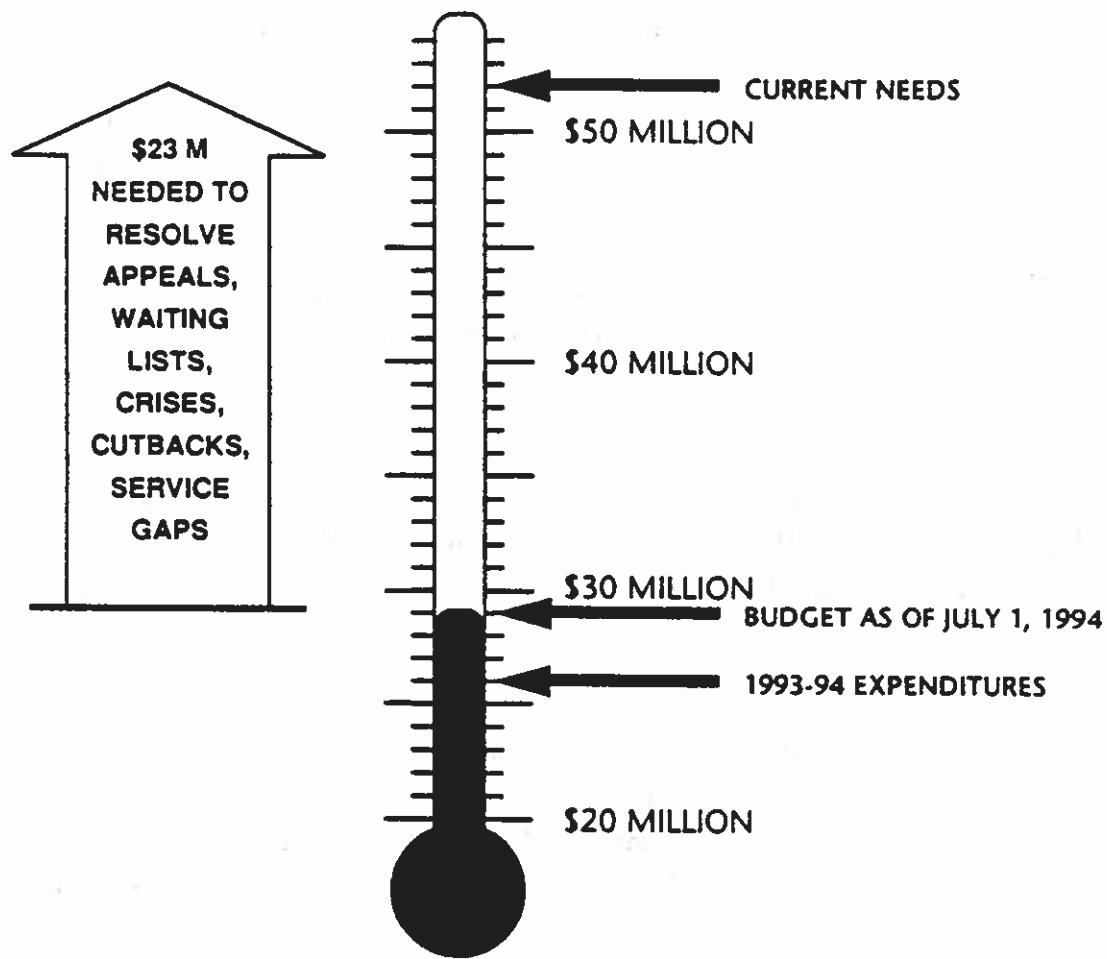


Figure 1. The Minister of Community and Social Services announced a \$3 million increase for Special Services at Home on June 30, 1994. The funding needed to address current needs is twice the 1993-1994 level. The required increase of \$23 million represents only 2.6% of the Developmental Services budget of \$894 million.

NOTE: The actual SSAH expenditure in 1993-94 was \$26 million — i.e. \$28 million less \$2 million for "Special needs, Phase 1" which is not really part of SSAH as reported in the financial estimates.

These are rough estimates, but they do show the order of magnitude of increase in SSAH funding required. We know that a \$3 million increase is not enough, that even a \$10 million increase is not enough, but that an increase of the same order as the current allocation of \$26 million is about right.

— Sources of funds for SSAH

Given the current fiscal restraints, we assume that the Ministry of Community and Social Services will have to address SSAH needs through internal reallocation. It is beyond our intentions to identify possible sources of funds in budgets outside the Developmental Services budget, although the Ministry should certainly consider such sources. We will limit our discussion to the Developmental Services budget.

The SSAH program budget is currently only 3% of the total Developmental Services budget of \$894 million. 97% of the Developmental Services budget is for Schedule 1 institutions, Schedule 2 institutions, and service agencies. As we indicate in the next section, SSAH is more cost-effective on the average than the existing service alternatives. Therefore, it is imperative to plan a shift in the funding from institutions and the less desirable segregated services to SSAH. This would be a reasonable response to the needs of both the consumers and the taxpayers (See Fig. 2). Otherwise, the consequences will be a growing deficit in supports and services, decreasing value per tax dollar, and immense dissatisfaction with the Ministry of Community and Social Services.

The SSAH allocation could be doubled with a 3% decrease in the institutional and transfer payment budget (note that this is much less of a cut than many families receiving SSAH had to suffer this year — often near 50%). Some of the funding can find its way back to service providers who can charge for services targeted to meet the needs of persons who have SSAH funding. An increase in SSAH would be partly offset by lower costs to the health care system, as families would have more opportunities to avoid undesired placements in psychiatric hospitals and others, such as Bloorview Children's Hospital.

We also wish to point out that most SSAH funds are used to create jobs, including summer jobs for students. In 1994, the Ontario government allocated \$52 million to create summer jobs, some of which may have been of doubtful necessity. A portion of this allocation could have been made to SSAH to create very meaningful summer jobs.

YOU BE THE JUDGE!

This is how the Ministry of Community and Social Services
runs the Developmental Services program.
Do you think it is doing a good job? Do you think it is fair?

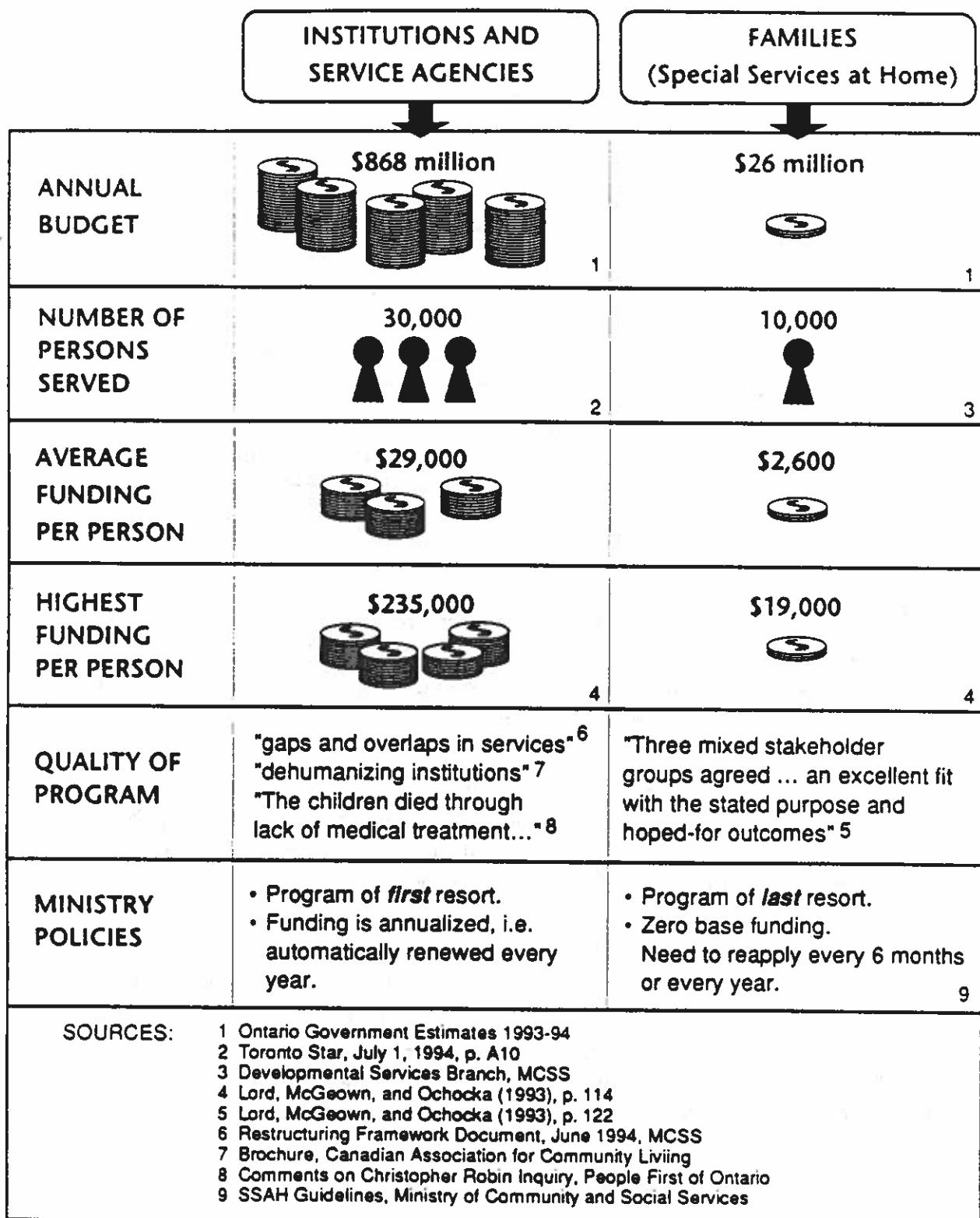


Figure 2. Comparison of SSAH Program with the MCSS service delivery system.

Finally, the Minister recently (June 30, 1994) announced reallocations of funds to various community services. It is still not too late to channel some of these funds through SSAH, giving *consumers* the say over exactly which services are ultimately funded.

Can the Ministry of Community and Social Services afford to double the SSAH budget? **It can't afford not to!**

2. SSAH should be recognized as a first-choice option

— Program effectiveness and the family advantage

Families have an advantage over service providers when it comes to planning and monitoring a program for a son or daughter with special needs. Parents know their children very well, usually better than anyone else does: the result of a natural bond and a lifetime of association. With few exceptions, parents are more committed to the welfare and success of their children than any paid worker can be. This knowledge and commitment are an excellent foundation for the functions of directing and monitoring a program.

The United Nations General Assembly has declared 1994 as the International Year of the Family. We fully agree with its tenet that the family is the *best framework for the emotional, financial and material support* essential to the growth and development of all its members [including those who happen to have a disability].

When professional services are needed to implement a plan, they can be purchased. Planning, administrative, and clerical skills can also be purchased. But the main function, that of overseeing and assisting the son or daughter with major decisions related to personal supports, is best left to a caring family or caring personal friends.

Indeed, the SSAH program has been proven to be highly successful. Lord, McGeown, and Ochocka (1993) have found that families and other stakeholders agree that the program is a success in general family outcomes, in community integration outcomes, in family life outcomes, and in skills and behavioural development outcomes — "Three mixed stakeholder focus groups agreed that these outcomes are positive and an excellent fit with the stated purpose and hoped for outcomes of SSAH. These focus groups also emphasized the preventative nature of these outcomes."

A LOOK INTO THE FUTURE — EVOLUTION OF PERSONAL SUPPORT SYSTEM AND SERVICE DELIVERY SYSTEM

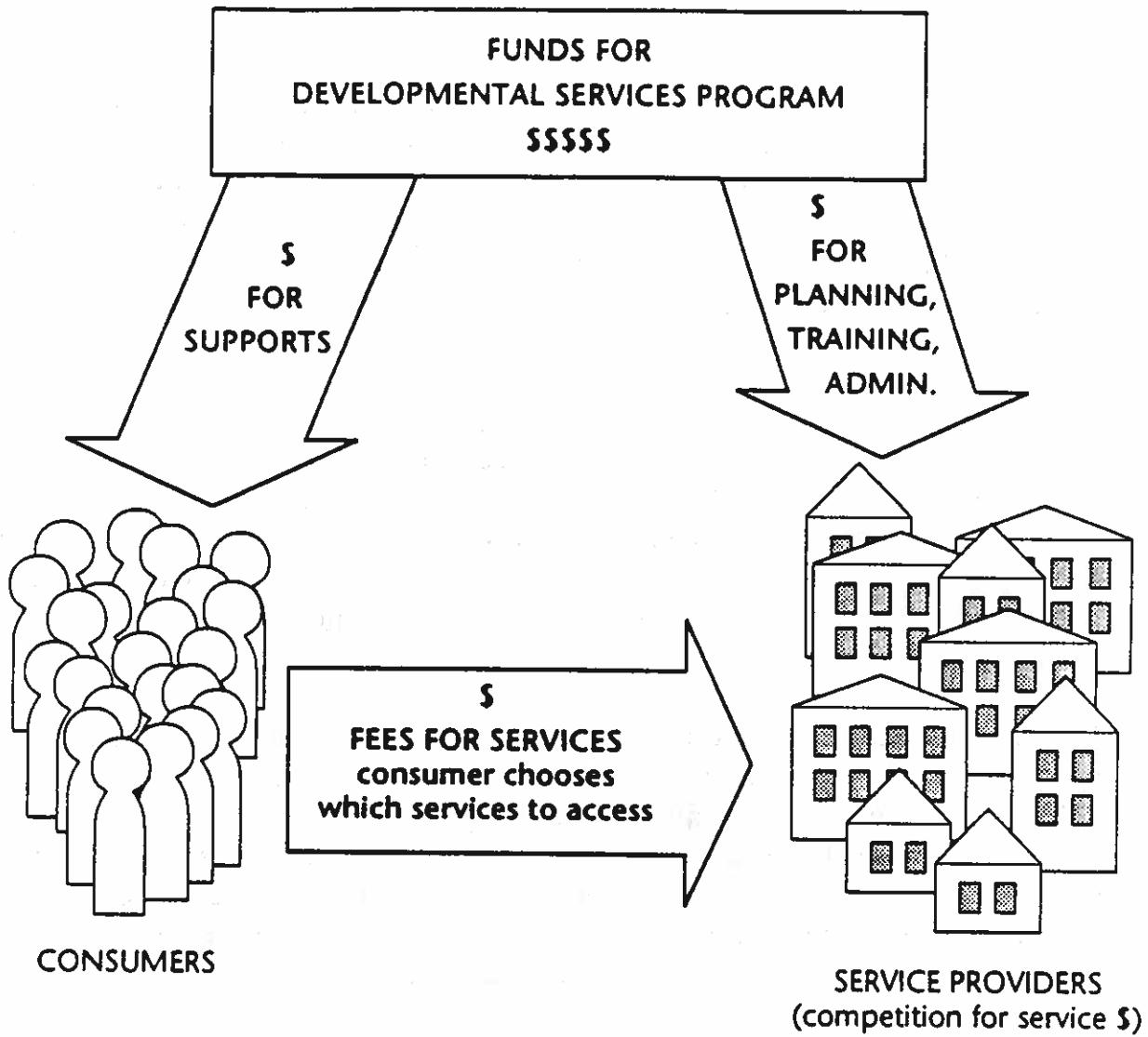


FIGURE 3. Illustration of what the Developmental Services system might look like according to the recommendations of Rioux and Crawford(1994). Services are funded on the demand side — funds are given to consumers according to their needs (individualized funding). Supply-side funding to agencies is limited to core functions such as administration, planning, and training. Agencies would charge user fees for the services they provide. The system is designed to give consumers control over what services they access, when, and from whom, and to make service providers more responsive and more accountable (directly) to the consumers. The concept of individualized funding is analyzed in *Direct Dollars*, Roeher Institute(1993).

The SSAH program is consistent with the principle of self-determination. Self-determination is not possible without control over the major decisions in one's life. Such control is impossible without control over personal support resources.

A recent policy paper by Rioux and Crawford (1994) of the Roeher Institute recommends that individualized funding be the basis for supporting the needs of individuals with disabilities (see Fig. 3). Two funding allocation streams are proposed — *demand-side funding* in which dollars would flow to consumers who would use the dollars to acquire the supports and services they need, and *supply-side funding* in which dollars would flow to providers of disability-related social services. The supply-side funding would be limited to core funding of administration and planning, with services being funded through user fees.

The authors state (p.7) " [demand-side funding] has proven to be an effective means of making social services more responsive and accountable to consumer demand. It introduces market forces and related efficiencies, lacking at present, into the social service sector. It is a means of containing costs in the sense that funds are allocated to actual requirements of individuals and over-serving is avoided. Demand-side funding has the advantage of providing enormous social and economic flexibility to the individuals being funded".

They also make the point that (p.54) "The proposed reform would put a delivery system in place that would respond accurately to individual requirements in a timely fashion and adapt as these requirements change. It would maximize flexibility in order to address community and individual circumstances. Correspondingly, the proposed reform would ensure responsiveness through individual and community planning." The concept of individualized funding is extensively analyzed in a another publication of the Rocher Institute (1993), *Direct Dollars*.

Our recommendation to treat SSAH as a first-choice option is consistent with these arguments for individualized funding. The only difference is that we are asking for an evolutionary step to take place in the right direction. We are not asking for an immediate revolution in the service delivery system.

Because individualized funding can be used very creatively and flexibly, it can be used to overcome gaps or inadequacies in the service system. Some families needing supports have experienced poor services from agencies and are seeking alternatives. For example, some families have taken their sons/daughters out of group homes

because they were concerned about the service providers' capability or willingness to resolve some serious problems that arose. Other families simply want to avoid the typical group home. They would prefer to make some alternative arrangements in which their son or daughter would have more decision making power.

Many families don't want segregated services such as sheltered workshops or segregated life skill programs. Yet the policy of the Ministry of Community and Social Services is to fund such programs to the detriment of the SSAH program. SSAH is the program with the highest potential for achieving community involvement objectives in *Challenges and Opportunities* (1987). Many services are labelled as community programs when in reality they offer little or no opportunity for integration into the life of the community at large. The policy of the Ministry of Community and Social Services is to refuse SSAH funding while insisting that people access such services because the Ministry funds them, even if the consumers don't want them, and even when the services don't exist!

— Cost-effectiveness

Figure 2 summarizes how cost-effective SSAH is, compared to the service delivery system. Even if the figures for SSAH are adjusted to reflect the increased funding we are requesting, SSAH is still a lot cheaper. As mentioned on p. 7, SSAH has less overhead because home and public facilities are used more extensively, because family members contribute their own time and effort free of charge, and because the program activities can be tailored to provide the exact level of support needed, exactly when it is needed (no more, no less). Families that receive needed supports are less likely to seek more costly institutional placements for their sons/daughters. We also strongly believe that children who are provided with supports at home and who experience interaction with the community are likely to have less demanding needs when they become adults.

The current policies of the Ministry of Community and Social Services are not cost-effective. As mentioned before, the Ministry prefers that consumers use the existing service delivery system even if it costs more. This also increases the costs of the health care system. If SSAH were accepted as a first-choice option, overall system costs would definitely fall. Cost-effectiveness should not be the primary criterion for designing a service delivery system, but it is a practical factor which affects feasibility.

Other factors which influence cost-effectiveness are competition between service providers, and responsiveness of service providers. As explained by Rioux and Crawford(1994), putting the dollars in the hands of the consumers will tend to make the service providers more responsive, more effective, and more efficient. If they have to rely on user fees for their services, their viability will be related to consumer satisfaction. Thus individualized funding such as SSAH helps to increase cost-effectiveness of the whole service delivery system.

— First-choice option

The current policy of the Ministry of Community and Social Services to treat SSAH as a choice of last resort is irrational and counter-productive both for program effectiveness and cost-effectiveness. In the end, why should not parents have the choice of which program to use? We have to remind ourselves of the fundamental issue — *“Whose life is it anyway?”* What right does the Ministry have to make these decisions that affect the lives of our children? Don't give our children's money to institutions. We don't want to listen to any more rhetoric about empowerment of consumers. Give consumers individualized funding and you will see empowerment.

3. The SSAH program should be broadened

— Addressing service gaps and deficiencies

In spite of the long history of the service system in Ontario, and in spite of grand objectives in Ministry of Community and Social Service documents such as *Challenges and Opportunities*(1987), there are still serious problems with services, as the Ministry points out in its *Restructuring Framework Document*(1994). To us, this is not surprising, because the service system is not directly accountable to consumers, as explained in the previous section. We believe that the most effective way of addressing service gaps and deficiencies is to broaden the terms of reference of the SSAH program so that consumers can apply the funds to meet such needs.

We strongly support the recommendations that have already been made by the SSAH Reference Group(1993), but *our sense of urgency is greater*. We want to highlight the following needs:

- Parents who do not want to place their sons/daughters in group homes, but who want to implement a better model in which their sons/daughters have

more control over their lives, do not have any program to turn to. The Ministry of Community and Social Services has shown no desire to address this need, as evidenced by its response to parents who are currently seeking funding for such purposes. Extending the SSAH terms of reference to address this need would be an effective and simple approach to this need. This could be done immediately (with the Minister's recently announced re-allocations) for those parents who are currently seeking funding.

- Some people with disabilities need vocational services but Vocational Rehabilitation Services consider them too hard to serve. In some instances, VR services have been accessed but have been ineffective. Parents want the option of using SSAH for vocational training. Current policies are arbitrary and counter-productive.
- SSAH funding needs to be portable. The Ministry of Community and Social Services can't seem to figure how to move funds from one Area Office to another. The portability barrier is unacceptable.

Rioux and Crawford(1994) (p. 57) say "Policy and programming must enable the disability-related supports to follow individuals as they make transitions across situations. Transitions occur within and between housing, education facilities, and worksites, as well as commercial, recreational, health-related and other environments. Personal attendants, aids, devices and translation services would be attached to individuals on an as-required basis, not to institutions or programs."

- Arbitrary exclusion of out-of-pocket expenses in SSAH is unfair and detrimental. Expenses such as for program transportation costs, extra fees, professional services and special equipment are allowed for institutions and service agencies but not allowed for families. In some cases, the viability of a program is affected, such as when a family cannot afford the transportation costs.

The SSAH program must be broadened in a serious attempt to make the support system "seamless". Arbitrary barriers designed by bureaucrats simply ensure that gaps will be inevitable. Some people always fall in between service categories. Let's resolve this immediately, without embarking on another 5 or 10 year plan.

CONCLUSIONS

Our studies clearly show that implementation of individualized funding would lead to better and more cost-effective supports to persons with disabilities. As we share our learnings, we find that consumers readily and strongly agree with the logical consequences of the individualized funding model. They are beginning to realize that there can be a better system for delivering supports and services. The political pressure for change will increase.

The concepts are also appealing to taxpayers, as they are familiar with the concept of market forces, and they can relate to the concept of service providers competing to respond to consumer needs.

The SSAH program has been intensively studied over the last four years by the SSAH Reference Group. So far the Developmental Services Branch has been extremely slow and tentative in implementing any of the Reference Group recommendations, but there is no reason for any more delay. In the case of our own recommendations, there is also no reason for delays. The arguments for individualized funding are strong and clear.

Finally, we have to say it again: *"Whose life is it anyway?"* No bureaucrat has the right to control the lives of our sons and daughters in matters as vital as the personal supports they need for the rest of their lives. Families should not be forced to use services that they consider to be inappropriate. It is time to start implementing evolutionary changes in the direction of increasing individualized funding and increasing accountability to consumers.

SUMMARY OF RECOMMENDATIONS

1. The budget for Special Services at Home needs to be doubled from the 1993/1994 level.
2. SSAH should be recognized as a first-choice option.
3. The SSAH program should be broadened to include adults not living with their parents, to fund vocational training, to be portable across Ontario, and to fund out-of-pocket and professional expenses.

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The Special-Services-at-Home Family Alliance — Who we are

The *Special-Services-at-Home Family Alliance* is a network of families across Ontario with sons, daughters, brothers or sisters, who have a developmental or physical disability, and who require special supports which could be funded through the Special Services at Home program of the Ministry of Community and Social Services. The Family Alliance is an independent association of families representing a broad spectrum of cultural backgrounds, experiences, and needs; it does not represent any service or fund-raising agency.

The Family Alliance believes that the family is the best framework for the emotional, financial and material support essential to the growth and development of all its members, including those who happen to have a disability.

The Family Alliance also supports the principles of community integration, empowerment, and self-determination of persons with disabilities. These cannot be achieved unless the persons with disabilities have control over the major decisions in their lives — such as — where they live, whom they live with, and what they do with their lives. The power to make decisions requires control over the financial resources allocated for personal supports. For persons who need assistance with personal decision making, the family is usually the most committed and most accountable source of guidance and support.

The *Special Services at Home* program, of the Ontario Ministry of Community and Social Services, is a very successful program because it takes advantage of the knowledge, commitment, and competence that families can apply to face challenges related to disabilities. This program empowers persons with disabilities through individualized funding, giving them and their families the financial resources to purchase the special supports and services that they need.

The Family Alliance believes that the Special Services at Home program can be the foundation for a much more general framework for funding supports for persons with disabilities, including those persons who do not live with their families. We believe that a broadened individualized funding program is also good for the taxpayers of Ontario because it increases efficiency and accountability by introducing market forces into the social service sector.

The Special Services at Home Program

The Special Services at Home program provides funding directly to families to support the special needs of children who have a developmental or physical disability, and adults who have a developmental disability who are living at home with their families. To be eligible, they must have an ongoing functional limitation as a result of a disability and must require support beyond that which is a normal family responsibility.

The program is designed to meet needs related to personal development and growth and/or family relief and support. Some specific services are not eligible for SSAH funding. For details, the reader is referred to the *Special Services at Home Guidelines*, available from the Ministry of Community and Social Services.

Families can apply at any time. They have the right to make a formal appeal if they are not granted the funds that they applied for. There is no limit to the amount that they can apply for, but amounts over \$10,000 are considered extraordinary and require the approval of the local Area Office manager.

The program was established in 1983 and has grown over the years. In 1993/1994, it supported 10,000 families in Ontario. The average grant was \$2600. and the largest grant was probably about \$20,000. The funds are used mostly to hire support workers. Families may administer the contracts themselves, or they may use the help of a service agency.

