SSAHPC

SOCIAL EXCLUSION?

How Government Programs Are Failing Persons with Developmental Disabilities

A Position Paper
Special Services at Home /Passport Coalition (SSAHPC)

June 2012

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HOW GOVERNMENT PROGRAMS ARE FAILING PERSONS WITH DEVELOPMENTAL DISABILITIES

Introduction

The Special Services at Home /Passport Coalition (SSAHPC) is deeply concerned with this Government's failure to effectively transform developmental services in Ontario. Although the Government says it promotes "social inclusion", thousands of people with developmental disabilities[1] are at risk of social exclusion.

The SSAHPC has consulted with the Ontario Government for more than thirty years - since the inception of the Special Services At Home program. We have always clearly articulated that SSAH provides an excellent way for individuals to direct individualized support to enhance their inclusion in community.

This paper will primarily focus on the programs available to adults in Ontario. In particular, we will discuss specific programs, initiatives and legislative reforms. We will demonstrate how chronic under-funding of developmental services and supports fails to transform the lives of persons with developmental disabilities. We will also show that people with developmental disabilities are not afforded any rights or recourse to challenge the supports and services they receive; legally they remain recipients of care, and are not engaged in determining the supports and services they want as individuals and as citizens. The paper will also consider some issues relating to the Special Services at Home program for children.

Special Services at Home – Context and Concerns

The Special Services at Home (SSAH) program was introduced in 1982, as a way to assist families and prevent the admission of children with developmental disabilities to government-run institutions. This program saved the Government millions of dollars, by allowing children to stay at home with their families and to participate in their communities. SSAH was expanded in 1990 to provide support to two other groups: children with physical disabilities and adults with developmental disabilities. The Government said that individuals with developmental disabilities and their families could use the funds received from this program in an individualized fashion to promote independence and to support community participation. Funds received by families could also be used for respite.

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[1] In this paper, we use the term "developmental disability" as this is the term used in the various programs and legislation we discuss. In doing so, we note that there are various views regarding the most appropriate language and we defer to members of the community and people with disabilities themselves regarding appropriate terminology.

However, since 2008, a very few applications for SSAH have been funded. Some people found eligible for the program before 2008 still have not received any funding, nor have people received promised increases in funding. They have been placed on a waiting list that continues to grow. Despite this grim reality, the Government continues to encourage people to apply for SSAH in order to gauge demand for the program.[2]

The following statistics about SSAH funding have been gathered by SSAHPC, Family Alliance Ontario, ARCH Disability Law Centre (ARCH) and the Auditor General:

- In the 2003/04 fiscal year, 23,790 applications for SSAH funds were received, and 20,657 were approved.
- In the 2009/10 fiscal year, the government received 32,705 applications, while 25,110 of those applications were approved for funding.
- Families have been told that they could apply for as much as $10,000 a year, but in March 2010, the average SSAH allocation was $4,201 per person annually.
- It is important to note that as the demand for funding increased, so did the waiting lists for funding under the program.
- As of March 2010, 7,160 applicants were on the waitlist – receiving no funding.
- According to the Auditor General of Ontario's Report, as of March 31, 2011 there were 9,600 people on the waiting list. All these families have been found to be eligible for SSAH funding, but received none at all.
- In 2011, the Ministry announced $40 million in new funding for Developmental Services, of which $4 million was allocated in SSAH to 955 adults who had previously been on the waiting list.[3]
- The only way that any other people on the waiting list have received SSAH is through "attrition recoveries" – using money previously allocated to others, but no longer utilized, sometimes due to death.[4]
- Families have not received increases in SSAH to respond to changing and increasing needs, nor to pay support workers more competitive wages, instead being told to reduce support hours if they wish to pay higher wages
- Effective April 2012, the Government announced – without consulting with the SSAHPC – that SSAH funding will no longer be available for adults.

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[2] ARCH Alert January 31, 2011 www.archdisabilitylaw.ca

[3] June 10, 2011 memo from Gaston Gauthier, Manager, Special Needs Program to Special Services at Home Coordinating Providers in the South West Region

[4] Ibid

The SSAHPC asks why the Government would not consult with us on the dismantling of a program that has long supported the unique services and supports required by individuals with developmental disabilities?

The SSAHPC also asks the Government to explain how individuals and their families will support and provide for themselves now that SSAH is no longer available to adults with developmental disabilities?

Passport Program – Context and Concerns

The Government introduced the Passport program in 2005. One stated purpose was to assist young adults with developmental disabilities who were graduating from high school to transition to community life by fostering skills development leading to independence and autonomous decision-making. Other older individuals living at home with their families are also eligible to receive some support through Passport. The funds received under this program are individualized for each person to promote participation in the community, continuing education and personal growth.

The Government's recent decision to cancel SSAH funding for adults means that Passport will now become the only avenue for direct funding for adults with developmental disabilities.

The following statistics about Passport have been gathered by the SSAHPC, ARCH and the Auditor General – revealing problems that are even more alarming than for SSAH, especially for young people who are no longer attending school, and whose families received no support:

- As of March 2010, 2,492 adults had received Passport funding, and there were 3,959 adults on the waiting list for Passport funding – all found to be eligible for funds, but receiving none.
- In the 2010/11 fiscal year, 2,700 people received a total of $31 million (or an average of $11,500 each) in Passport funding. In addition, there were approximately 4,500 people who had been determined to be eligible, but who were on the Passport funding wait list, receiving no money.
- In June 2011, the Ministry announced an $11 million increase to Passport – apparently providing funding to 955 more people who had been on the Passport waiting list[5]. The Ministry does not say how many more peoples' names were added to the waiting list since March 2011. How this money was allocated seems to have differed throughout the province.
- The discrepancy is shocking. Fewer people receive funding than are on waiting lists for funding.

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[5] Ibid and MCSS Spotlight on Transformation, June 2011 stated that 955 (half of 1910) people would come off the Passport waiting list, which would reduce it by 20%.

- To make matters worse, some people have been on the waitlist for years, and despair of ever receiving the funds necessary to allow them to engage in skills development and personal growth necessary for community participation and community life.
- Many others may not have applied, realizing that money is not available.
- To illustrate the impact on those leaving high school in particular, there are enormous repercussions for young adults and their families:

    - Important skills learned during high school may be lost.
    - In families with two income earners, many will be forced to reduce their income to one source, since one parent may be required to stay home to provide supports and assistance for the young adult.
    - Single parents risk their entire livelihood.
    - This can have a huge impact on housing, standards of living and on the whole family.
    - Siblings may be denied opportunities they had hoped for because of resulting financial pressures.
    - Families already provide considerable unpaid support and cannot afford to pay more for workers to support their son's or daughter's life in their community.

As of April 2012 young adults applying for Passport funding must undergo a Supports Intensity Scale (SIS) Assessment. This tool was intended to provide a more transparent decision making process. However, criteria for funding remains unpublished, and the people making such decisions unidentified.

April 1st 2012 to March 31st 2013 is a transitional year for the Passport Program, and issues of concern arise as it becomes the vehicle or platform for direct funding for adults with a developmental disability.
Two types of service/and or program are funded:

- Respite/Personal Development, and Growth (formerly SSAH), and
- Community Participation Supports (original Passport).

Each of these, as listed on the Passport Program Invoice for 2012/13, has different reporting methods and different rules for the use of funds. It is unclear in the revised Passport model whether direct funding can be used for regular personal care such as bathing, dressing, feeding etc., essential for some people to enable their participation in the community. Overnight/evening supports for individuals living with their families or in their own home are not funded by either of these types of service.

People receiving direct funding from Passport to live, work and play in their community benefit greatly from on-going independent facilitation support in order to use their funding in a well planned, goal oriented, cost effective and valued way. Although individuals may use up to 10 percent of their Passport funding for administration and/or independent facilitation, this would take too much from people's already inadequate funding, and most individuals and families cannot afford to take 10 percent away from their basic support hours. Independent facilitation needs to be funded separately and adequately to support people and families who choose direct funding. Without separately funded independent facilitation, people will not have access to quality support to: make decisions, create unique and good lives within community, weather conflicts and crises as they occur, and interview, hire and maintain good supporters.

The SSAHPC asks: When will adequate and ongoing independent facilitation support be available to individuals and families who receive direct funding?

The SSAHPC asks: how can a program be considered a viable one if so few people benefit from it?

MCSS has created a crisis for young adults with developmental disabilities

Ontario families are devastated to learn that progress made in 1990 has been undone as of April 1, 2012 – as adults with developmental disabilities are no longer eligible for SSAH after their 18th birthday.

The MCSS website[6] says: "*Passport is changing. Starting April 1, 2012, direct funding for adults with a developmental disability is available through Passport.*"

- This is not true - new Passport funding appears to be totally *unavailable*!
- Many adults with developmental disabilities require much more support than Passport can provide (to those for whom it is currently available).
- Adults who were already waiting for SSAH seem to be forced now to join all of those already in the Passport queue.
- If families break down under the stress, there will be urgent pressure for more costly, segregated services.

The May 2012 Spotlight on Transformation directs families to the MCSS website to "find out more", but answers are not provided and sections quoted below raise the following questions and concerns about what will happen as of April 1, 2013[7]:

- "We are expanding the Passport guidelines to cover a broader range of services."
    - Passport does not cover all of the kinds of support adults with developmental disabilities may require.
    - Passport provides NO funding for those still attending school and who will no longer receive SSAH. Further, those who do leave school face the prospect of languishing for years on the Passport waiting list.
- "Having a single direct funding program for adults with a developmental disability will make it easier for them to apply for services and supports."

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[6] http://www.mcss.gov.on.ca/en/mcss/programs/developmental/serviceSupport/passport.aspx

[7] http://www.mcss.gov.on.ca/en/mcss/programs/developmental/serviceSupport/passport_change.aspx

  - All adults previously eligible for SSAH will apparently need to re-apply for Passport funding by April 1, 2013 through Developmental Service Ontario (DSO).

- The Ministry says DSO was created to "help people get access to services more easily… to help more people and to ensure that we use fair ways of deciding how much support each person needs. It will also give people with developmental disabilities more choices".
  - Adults will be forced to undergo psychological assessments (at whose expense?) to prove eligibility.
  - DSOs will have to assess potentially thousands of adults seeking Passport funding according to the Supports Intensity Scale (SIS) before April 1, 2013
  - It is unclear whether SIS is still being piloted. There is no transparency in the relationship between SIS assessment information and Passport funding "bands"[8]
  - DSOs will be required to respond to families in crisis if Passport funding is not available

- "SSAH is for children only."
  - This arbitrary MCSS decision appears intended to take funding away from adults because so many children and youth have been unsupported for so long on the SSAH waiting list.
  - It is unacceptable for government to pit families against families, to compete for entirely inadequate amounts of direct funding.
  - Families of younger children are shocked when they find out that support is not available for adults now, and despair that it will not be available in their future either.
  - All those seeking cost-effective and inclusive supports through direct funding are appalled that government is not improving life-long opportunities for people with developmental disabilities.

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[8] http://www.mcss.gov.on.ca/en/mcss/publications/developmentalServices/passportGuidlines/section2.aspx :
The amount of funding available for an individual plan is based on the application of funding bands which correspond to four categories of support:

Category of Support	Funding Bands
Low / Minimal	up to $6,250
Medium / Moderate	$6,251 to $12,500
High / Significant	$12,501 to $18,750
Exceptional	$18,751 to $25,000

Innovative Residential Model Initiative

In 2006, the Government introduced the Innovative Residential Model Initiative stating that it would:

> "give adults with a developmental disability and their families the opportunity to propose individually tailored residential services concerning where and how they live. Working together, individuals, their families, and service providers can develop housing options that are best suited to their personal needs, wants and dreams."[9]

However, the first Regulation under the Initiative excludes people who receive direct funding from accessing the funding available to agencies for residential supports and services. The SSAHPC wonders how soon portability will be put in place to enable people to be able to live where they choose with the supports that they need? We also wonder how MCSS can ensure that these dollars become direct funding if the person and their family choose this, i.e. if a person who currently receives agency supports prefers a direct funding option? To deny a whole group of people with developmental disabilities from the benefits under this initiative undermines the government's stated objective. Housing options are not available. As it stands, people with developmental disabilities will only be granted funding through one route – residential support through agencies – otherwise there appears to be no support at all for living in one's home of their choosing.

When considering all that "transformation" should involve, the Ministry of Community and Social Services (MCSS) asked families to suggest creative housing and community supports, which very often rely on direct funding. But MCSS rules continue to force people into the more traditional segregated models of residential support, such as group homes. Therefore, what Developmental Services Ontario says[10] is not true – direct funding does not give people more choice and flexibility.

The SSAHPC asks when funding will be available for this initiative. We believe that people need enough direct funding to be able to move from segregated settings, or to live separately, if they choose, from their family and loved ones. We believe that direct funding must be available as an inclusive and cost-effective alternative to residential services.

The SSAHPC asks: is it fair, or innovative, to deny some people access to support dollars to live in their own homes?

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[9] http://www.ontla.on.ca/library/repository/mon/19000/276923.pdf

[10] http://www.dsontario.ca/direct-funding

Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act

When the Government adopted the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (the *Social Inclusion Act)* in 2008, the purpose was to shift Ontario's developmental services sector away from institutionalization, and to provide for community delivered supports and services that would promote the inclusion of people with developmental disabilities. This would offer people the opportunity to be more independent and have more autonomy over personal decision-making in order to meet unique wants and needs and to realize their own dreams and ambitions. Sadly, the Government's promise has not been honoured. Transformation of developmental services has eluded the majority of people with developmental disabilities and their families.

The large institutions in Ontario were finally closed in March 2009. The *Social Inclusion Act* came into force in staggered stages, starting in January 2010. Nevertheless, community-based supports and services for people with developmental disabilities have not increased.

The SSAHPC asks: How much of the budget saved in the 3 years since institutions closed has actually gone to create new kinds of support for people with developmental disabilities? How much of the money saved has gone to support agency infrastructure? How were the funds from the institutions' budgets re-allocated?

- SSAHPC members learned that government institutions cost more than $100,000.00 per person per year – 18 years ago[11]!
- People receive an average of $11,500 a year if they can access Passport funding; but 4500 eligible people receive nothing[12].
- Families receive an average of about $4,200 a year if they access SSAH[13]; but 9600 eligible families receive none[14].

The *Act* allows direct funding whereby individuals and their families can identify the unique kinds of supports and services that will enhance opportunities for people with developmental disabilities and relieve some of their families' financial pressures. This means that each person with a developmental disability can have more opportunity to make choices. Direct funding provides a tremendous opportunity for individually tailored supports that will correspond to the broad spectrum of needs of people with developmental disabilities.

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[11] Family Alliance Ontario documents: "9000 Families Can't Be Wrong" (April 1994) and "Families Do It Better" (July 1994)

[12] Auditor General, 2011

[13] ARCH research March 2010

[14] Auditor General, 2011

The SSAHPC asks again: how it is fair or innovative, to deny some people access to funding to live in their own homes? We ask that Regulation 276/10 of the *Social Inclusion Act* be amended to include an additional class of supports and services eligible for direct funding. This would provide for "home living supports" comparable to those available to people living in agency funded residential supports.

In addition, a number of problems have been identified with the *Social Inclusion Act*. People have little or no control over funding decisions that are made, nor are these decisions made in a transparent and open manner. As of April 2012, young adults applying for Passport funding must undergo a Supports Intensity Scale (SIS) assessment. People are being forced to relinquish privacy rights without any knowledge of how their assessment information will be used, and without any assurance of requisite support. Chronic under-funding of programs means that even those with the highest needs might receive no financial support at all. Very few people with developmental disabilities receive community supports and services to advance their citizenship, dignity, independence, autonomy and inclusion. Some individuals may receive funding allocations because of attrition, which likely means that another person has died. When regions can show an increase in numbers of individuals supported by meager allocations, it may be less likely that those with the highest needs ever actually come off the waiting list.

In addition, the use of a SIS assessment further entrenches a deficit-based, medical model of disability into the identification of a person with a developmental disability. The SSAHPC asks how the inherent adoption of a deficit-based model, which locates "problems" in the individual, promotes inclusion? The social model, which considers external barriers and obstacles to full participation is one that has gained recognition in Canadian society, and indeed, by our highest Court.[15] The tacit acceptance of the deficit-based medical model that underpins this legislation is a step backward for all people with disabilities.

Moreover, the *Act* has been criticized for omitting two major and critical benefits for persons with developmental disabilities. First, it does not include substantive rights for persons with developmental disabilities when they receive disability supports and services. Rather, it focuses disproportionately on details of service provision and funding without sufficient regard to the impact that these programs have on people with developmental disabilities. As Kerri Joffe, a lawyer with ARCH says in a paper commissioned by the Law Commission of Ontario:

> "A system that truly supports the full participation, dignity and citizenship of people with intellectual disabilities must enshrine substantive rights in legislation… This would allow people with intellectual disabilities to

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[15] Granofsky v. Canada (M.E.I.) [2000] 1S.C.R. 703

> become active consumers of services …rather than remaining passive recipients of care”.[16]

Furthermore, there are no robust enforcement mechanisms for people with developmental disabilities to enforce any rights. There are minimum government standards for quality control measures that apply to agencies who administer funding or who process applications for funding. The agencies are subject to standards that are enforced through self-reporting, inspections, orders, government oversight or possibly government take-over of agencies. But nowhere are there appeal rights or ways to enforce the rights of people with developmental disabilities themselves.

The failure of the legislation to address rights, complaints and appeals, and abuse causes great concern that the lives of people with developmental disabilities will not be improved notwithstanding legislative reform. Individuals are left with no recourse if they are mistreated, abused or unhappy with services.

The SSAHPC asserts that absent of any rights and any robust enforcement mechanism to ensure that rights are respected; people with developmental disabilities will live in a culture of fear and reprisals if they do complain about their services and supports. Furthermore, they are subject to attitudinal barriers that involve stereotypes and discriminatory ways of thinking that undermine their independence, autonomy and choice and that under-value their right to citizenship.

Recent Developments

The Auditor General’s Report 2011

Chapter 3 of the 2011 Auditor General’s Report is entitled Supportive Services for People with Disabilities. It provides a scathing review of the problems associated with transfer payment agencies and the SSAH and Passport programs. Indeed, the Report states that many of the problems that were identified with supports for persons with disabilities fifteen years ago have still not been addressed. These include:

- no adequate quality assurance measures
- a lack of Ministry oversight of the programs that would ensure accountability for the expenditure of public money.

Specifically, the Report found that:

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[16] Joffe, K., Enforcing the Rights of People with Disabilities in Ontario’s Developmental Services System p.23

- Documentation was lacking to support how decisions about funding were made, how eligibility is determined or how funding amounts allocated met identified needs.
- The Government is not aware of the extent of unmet need based on waiting list information.
- Transfer payment agency funding is based on historical need, and has not been reviewed and updated to take into account the range of needs or the costs of services across the province.
- There have been excessive expenditures by transfer payment agencies on items that do not follow Ministry guidelines, such as meals, gifts and fitness club memberships for managers.
- The Government's freeze on SSAH funding since 2008 has led to a huge gap between growing demand and available funding.
- Over 14,000 people had been deemed eligible for SSAH or Passports, but received no funding.
- There are particular problems with the Passport program.

The government's response was that its process of "transformation" of the developmental services sector would address the problems identified by the Auditor General.

The SSHAPC asks when will real transformation finally take place? How will the Government measure success in transforming developmental services?

Social Assistance Reform in Ontario

As part of its 2008 Poverty Reduction Strategy, the Government established a Commission for the Review of Social Assistance in Ontario. The Commission's mandate was to undertake a comprehensive review of the Ontario Works and Ontario Disability Support Programs and to provide the government with a concrete action plan to improve these two income schemes for Ontarians who experience poverty.

The first discussion paper published by the Commission in June, 2011, was entitled "Issues and Ideas". The second paper, released in February 2012 was called "Approaches to Reform".

It is undeniable that living with a disability and poverty are inextricably linked.[17] So are poverty and social exclusion. Any changes to the Ontario Disability Support Program (ODSP) are therefore critically important to people with developmental disabilities and their families.

"Approaches to Reform" emphasizes that engaging in employment activities is the first step out of poverty for most people in receipt of social assistance. This

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[17] Eldridge v. British Columbia (Attorney General), [1997] 3 S.C.R. 624

includes people with disabilities who are in receipt of ODSP. For those who are unable to work, “Approaches to Reform” proposes to create a separate category for people with “severe” disabilities. This contradicts the present definition of disability - which requires that a person demonstrate that they have a “substantial impairment” that has a “substantial impact” on their ability to perform activities of daily living. The proposed category of “severe” disabilities would likely mimic the former category of permanently unemployable people, under the *Family Benefits Act.* We remember that people with disabilities found that category to be an insulting one; just because someone has a disability does not mean they do not want to give back to their community, whether through paid employment, volunteer activities or in some other way. The SSAHPC believes that no one who wants to work should be dissuaded from doing so, with access to appropriate employment and/or community supports. It is equally important that someone who has been found to be a person with a disability should not be forced to engage in employment activities in order for them to be “lifted out of poverty”. Employment must be voluntary and therefore income supports under the Ontario Disability Support Program should be enough to provide for an adequate standard of living.

Employment Supports already exist under the *Ontario Disability Support Program Act.* Their ineffectiveness can be connected to the fact that they are insufficient for a person with a developmental disability to maintain employment over a long period of time – at present, they pay service providers to place people in jobs without regard to either the quality or longevity of employment.[18]

The SSAHPC believes that whatever recommendations are made by the Commissioners should be consistent with the values we espouse: citizenship, inclusion, autonomy, independence and dignity.

Results from the Survey of People Receiving Residential Supports

Since its inception, the SSAHPC has contrasted the high costs of government institutions, the budgets of residential and other agency programs, and the funding available through SSAH to families. In 2007, it prepared a graph, showing $1.4 billion spent that year on 40,000 people in agency programs versus $95 million in SSAH funding that was spread among 27,000 families[19]. The government spent ten times as much per person in agency programs. Waiting lists keep growing while MCSS is now forced to do more with available funds. The provincial auditor said that funding should relate to the “needs” of those it supports.

In November 2011, the Ministry of Community and Social Services conducted a

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[18] Community Living Ontario, Response to the commission for the Review of Social Assistance in Ontario Discussion Paper 2: Approaches to Reform, p. 2

[19] http://www.ssahcoalition.ca/latest_facts.htm

Survey of People Receiving Residential Supports. Although more objective information might have been available through Supports Intensity Scale scores, this research asked service providers to report the “needs” of the people for whom they receive funding. Agencies that set their own admission criteria might prefer to choose those who will cost them less and be easiest to manage, but this research might amplify the needs of people receiving agency services, in these ways:

- The graphics in this document illustrate that the majority of people who receive residential services actually use few supports and services. For example, they do not require mobility aids or feeding assistance, never demonstrate behaviour challenges, and are not experiencing sensory deficits.
- One third of those considered to be receiving residential supports were living alone, partnered or not receiving help every day.
- Agency staff reported almost 3000 “undiagnosed” mental health disorders, dementia, epilepsy, diabetes, acquired brain injury, autism, asthma, and rare developmental disorders. Qualified professionals had not made any of these diagnoses.
- Agencies were asked to presume which residents did *not* actually exhibit behaviour problems but *might,* if they were not properly supported.
- Very few of the people in residential programs receive assistance from communication consultants, but agencies report that 573 people “rarely or never express themselves” – use no words, signs, gestures, devices, sounds and utterances, not even facial expressions.

The SSAHPC wonders: could this research be used to compare the needs of people who already receive residential services with those who access or wait for direct funding such as SSAH and Passports?

Will government review data collected through the SIS process to more objectively assess the needs of people already receiving agency-funded services? Will summary data be published in the interest of fair and equitable provision of services for all persons with developmental disabilities?

Families who deal with significant mobility, dependency, behavioural, medical, communication and other needs of their son or daughter are often unsupported, financially or otherwise, 24 hours a day, 365 days a year.

Will the Government conduct a survey about the needs and circumstances of people who are in receipt of, or on the waiting lists for SSAH/Passport funding, to determine unmet need? Would such a research process allow individuals or their families to report undiagnosed conditions, presume about potential but non-existent problems, and amplify their sons’ and daughters’ needs?

2012 Provincial Budget

The Ontario Government's 2012 budget adopts the tone – and many of the austerity measures – of the Drummond Report. No new money has been allocated to the developmental services sector. A 1% increase was provided to recipients of social assistance after tough negotiations by the New Democratic Party. What is clear, however, is that no increase – or just a 1% increase - does not address cost of living increases, nor make even the slightest dent into the long waiting lists experienced by people with developmental disabilities and their families.

Summary

Ontario transformed the *Developmental Services Act* of 1974 because it had failed to acknowledge the basic tenets of the civil rights and community living movements: the right to full participation and inclusion in society, the right to equality and full citizenship regardless of ability, and the right to self determination. The system of developmental services that existed under the old act prevented inclusion and emphasized institutionalization. Funding programs used medically defined eligibility criteria, had unwieldy application processes, kept long waiting lists, and provided poor accountability.

Although the genesis of the new *Social Inclusion Act* was in response to Ontario's closure of government-run institutions, it fails to transform the system of services and entrenches many of the worst aspects of the old system. The medical model continues to dominate the legal definition of developmental disability and to define eligibility criteria for access to services and supports. The expensive bureaucratic infrastructure surrounding application, assessment and eligibility determination remains unresponsive and unfair to the individuals whose needs it is supposed to serve. The service delivery system demonstrates the close relationship between government and service providers. Accountability involves little or no reference to meaningful outcomes for people – ones they have chosen for themselves. People with developmental disabilities continue to have no control over the funding decisions or the type and amount of services and supports they receive.

Moreover, thousands of people with developmental disabilities continue to languish on waiting lists for individualized funding programs. Young adults risk losing the skills gained and connections made in high school that would allow them to participate in their communities. Pressures on families increase. Services delayed are services denied. By underfunding programs such as Passport, the Government continues to deny the right of thousands of people to participate in their communities.

As time goes by, more and more children do not receive SSAH, and then fall into the abyss of the Passport Program as they become adults. It is critical that the issues and concerns raised in this paper receive immediate attention. Self-advocates, families, organizations, associations and government bodies have a key role to play to make social inclusion a priority and reality.

The SSAHPC asks this government to ensure that people with developmental disabilities receive the supports and services necessary to participate in community life. The SSAHPC believes that implementation of adequately funded and equitable direct funding programs can lead to better and more accountable services and job creation. Without action, Ontario's government programs will continue to fail persons with developmental disabilities. We believe that the Ministry of Community and Social Services must open the doors for social inclusion for thousands of Ontarians to become full citizens of Ontario.

The Special Services at Home Passport Coalition/SSAHPC concludes:

- that MCSS "Transformation" is regressive, promoting exclusion not inclusion
- there are major problems with the Social Inclusion Act, and
- amounts available for direct funding are woefully inadequate

We, the families, have the same desires for all our sons, daughters, sisters, brothers and friends - to have a respected place in the community and to live, work and enjoy life like every other Canadian citizen. We are appalled that immense changes have been made to one of the most innovative programs designed by the government - without consultation.

Direct Funding - like SSAH and Passport - has immensely improved the lives of some people with developmental disabilities. Those who have accessed such help can participate more fully in community life. That means that their immediate and extended families, their teachers and classmates, and so many neighbours and friends, co-workers, employers, fellow taxpayers and other allies may now join together to ask for an immediate government response to the concerns and questions we share.

Summary of Questions and Concerns

SSAH

1. The SSAHPC asks why the Government would not consult with us on the dismantling of a program that has long supported the unique services and supports required by individuals with developmental disabilities?

2. The SSAHPC asks the Government to explain how individuals and their families will support and provide for themselves now that SSAH is no longer available to adults with developmental disabilities?

Passport

3. The SSAHPC asks when will adequate and ongoing, independent facilitation support be available to individuals and families who receive direct funding?

4. The SSAHPC asks how can Passport be considered a viable program if so few people benefit from it?

Innovative Residential Model Initiative (IRMI)

5. The SSAHPC asks how soon portability will be put in place to enable people to be able to live where they choose with the supports that they need?

6. The SSAHPC asks how MCSS can ensure that these dollars become direct funding if the person and their family choose this?

7. The SSAHPC asks when more funding will be available for this Initiative?

8. The SSAHPC asks how it is fair, or innovative, to deny some people access to support dollars to live in their own homes?

Social Inclusion Act

9. The SSAHPC asks how much of the budget saved in the 3 years since institutions closed has actually gone to create new kinds of support for people with developmental disabilities?

10. The SSAHPC asks how much of the money saved has gone to support agency infrastructure?

11. The SSAHPC asks how were the funds from the institutions' budgets re-allocated?

12. The SSAHPC asks how the inherent adoption of the Supports Intensity Scale (SIS), a deficit-based model, which locates "problems" in the individual, promotes inclusion?

Auditor General's Report

13. The SSHAPC asks when will real transformation finally take place? How will the Government measure success in transforming developmental services?

Survey of People Receiving Residential Supports

14. The SSAHPC asks could this research be used to compare the needs of people who already receive residential services with those who access or wait for direct funding such as SSAH and Passports?

15. The SSAHPC asks will government review data collected through the SIS process to more objectively assess the needs of people already receiving agency-funded services? Will summary data be published in the interest of fair and equitable provision of services for all persons with developmental disabilities?

16. The SSAHPC asks will the Government conduct a survey about the needs and circumstances of people who are in receipt of, or on the waiting lists for SSAH/Passport funding, to determine unmet need? Would such a research process allow individuals or their families to report undiagnosed conditions, presume about potential but non-existent problems, and amplify their sons' and daughters' needs?