



LEGISLATIVE ASSEMBLY

Queen's Park Office:  
Room 207 N. W.  
Main Legislative Bldg.  
Toronto, ON M7A 1A8  
Tel: 416-325-2244  
Fax: 416-325-2166  
E-mail: [randy.hillier@pc.ola.org](mailto:randy.hillier@pc.ola.org)

**RANDY HILLIER, M.P.P.**

Lanark-Frontenac-Lennox and Addington

1 April 2008

Madeleine Meilleur  
Minister of Community and Social Services  
80 Grosvenor St, 6th Flr, Hepburn Block  
Toronto ON M7A 1E9

Dear Minister;

I am writing you today in order to provide you with a report of my Community Forum entitled "Being Mindful of Intellectual Disabilities", which I hosted on March 11, 2008 in Carleton Place Ontario.

It is clear from the families affected that there are a number of failings with the current program delivery and funding models. The system is failing so many people- they fall between the cracks and end up joining the ranks of the homeless; too many do not have access to the medication and care that we, as a society, had promised them.

Shifting the funding model from a per-capita methodology to one that reflects the true nature of needs, such as the *Pressures and Priorities* evaluations described in the report, as well as attaching funding to the individual where necessary, will go a long way to ensuring that the funds already allocated to this sector are used effectively.

The delivery model must become more efficient. Asking families to go *cap in hand* to multiple Ministries and agencies pleading for assistance is, put quite simply, unacceptable. There needs to be one service window, one Ministry that takes responsibility for providing the necessary supports and services for these vulnerable individuals, and the Ministry of Community and Social Services is best suited.

Numbers from *Pressures and Priorities* for the South East Region show a trend of deficits; as of January 25, 2008:

- 234 people are on wait list for residential services such as group home and supported living
- 273 people are on wait lists for program services such as respite care, therapy, clinical assessment, behaviour management and similar services;
- 142 people are on wait lists for day program support services

I will be requesting a meeting with you in the future to further discuss the findings of this report and some real solutions to the problems these families and individuals face. My assistant will be in contact with your staff in order to schedule a meeting.

Sincerely,

Randy Hillier

**Constituency Offices:**

**Perth Office:** 1-105 Dufferin Street • Perth, ON K7H 3A5 • Tel: 613-267-8229 • Fax: 613-267-7398  
**Carleton Place Office:** 6 Lake Avenue West • Carleton Place, ON K7C 1L2 • Tel: 613-257-8130 • 1-866-277-1577 • Fax: 613-257-4371  
**Napanee Office:** 4 Market Square • Napanee, ON K7R 1J3 • Tel: 613-354-1948 • 1-866-929-0092 • Fax: 613-354-0924





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## **Being Mindful of Intellectual Disabilities**

On Tuesday March 11, 2008, MPP Randy Hillier hosted a Community Forum in Carleton Place Ontario

Entitled *Being Mindful of Intellectual Disabilities*, the forum was convened to examine the lack of services and supports being provided for families of people with intellectual disabilities, in order to better understand the problems and obstacles and develop some real solutions.

The following were the “official” participants from the government service agencies and service providers for this sector:

- Randy Hillier, MPP Lanark Frontenac Lennox and Addington (Chair)
- David Hagerman, and Tayside Community Residential and Support Options Director
- Georgina Thompson, Chair of the Board, Southeast Local Health Integration Network (LHIN)
- Steve Edmiston, Program Supervisor, Ministry of Community and Social Services (MCSS)
- Heather Wayte, Acting DS Program Manager MCSS
- Susan Geoffrion, Childrens' Aid Society (CAS), Lanark County
- Jeff Nault, Adult Protective Services, Lanark County
- Joyce Rivington and Cora Nolan, Family Voice of Lanark County
- Carol Anne MacNeil and Donna Davidson, Lanark Family Programs

Seventy people representing a cross-section of the community that depends upon these services and supports actively participated in the discussion, sharing their experiences.

Media included representatives from Carleton Place Canadian, CTV Ottawa and CBC Radio.

The meeting was a two-and-a-half hour event with a slight interruption as MCSS officials who left before the meeting's completion.

The meeting identified key problems in several areas, including:

- Program Inefficiencies
- Budgeting discrepancies
- Red Tape
- “Transition Age” Inequities

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### **Program Inefficiencies**

The Passport Program has been denying applicants almost from the moment it was introduced. The following represent a cross-section of application numbers from across the province:

- Hamilton, 174 applied, 6 were funded (3% of applicants);
- Peterborough, 102 applied, 7 funded (7% of applicants);
- Toronto 400 applied, 33 funded (8% of applicants);
- London area 262 applied, 11 funded (4% of applicants); and
- Windsor-Essex 120 applied, 6 funded (5% of applicants)

The Passport Program saw its budget decline from almost \$600k for our region to just above \$106k. Our region saw 229 applicants vie for a share of \$106,800.00 over three years. Five applicants were “successful”, a mere 2%. Nicolas Bell’s mother, who applied for assistance in caring for her autistic son, was one of twenty applicants who had the same “priority score” of 41, and were placed on a wait list. After 21 years of caring for her son herself, Karen York decided she needed help. Her reply had the same two sentences as so many of the others we have seen: “Unfortunately, your application cannot be funded at this time. However, Passport is an ongoing initiative and your application will be kept on file for the next three years and considered once additional funding becomes available.” How much is being spent on administering this program, which is funded to fail?

In August 2007, in another initiative, the government of Ontario announced \$276 million to “strengthen community supports for adults with a developmental disability”. In fact only about \$9 million has been allocated for families; it appears the rest may have been eaten up by wages and “revitalization of traditional agency infrastructure”.

### **SOLUTION:**

The funding model needs to be revised so that less money is going into administration and infrastructure and more money goes to the people who need it. When we see the money going into a program increase 37% over a period, and the number of people being served drop by 27% during that same period, we must re-evaluate our delivery methods, and remedy the administrative and regulatory problem that cause these shortfalls & hardships.

### **Budgeting Discrepancies**

The province spends a great amount of capital and effort into identifying those who have needs, identifying their requirements, and assigning a dollar value to these needs. One such program, called *Pressures and Priorities*, requires that families complete extensive paperwork and an intensive interview process in order

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for the right to stand in line or be denied service. Further, we have been informed that the information obtained through *Pressures and Priorities* is not even looked at when it comes time to define the budget.

Lack of funding often drives these families to look for cheap, under-qualified (often unqualified) help in order to meet the demands. In rural settings, most of their money is eaten up by transportation costs trying to get their loved one to services that help to provide quality of life, such as medical appointments, physiotherapy, and speech therapy. Families end up spending what little resources they have trying to establish their own service networks in order to create adequate care levels for their loved ones. Applications for charitable organization such as *New Leaf Link* flow in to the government from families desperate to create supports where the government will not. Community organizations are formed as families try to help each other cope, with varying levels of success, but none adequate to meet the needs. When the professional parents of a 31 year old young woman with Down's Syndrome spent their energy and life savings developing a creative and sustainable industry for their daughter and her peers to work in, the local agencies saw the value but did not have the funds available to carry it on. These aged parents now have serious health issues of their own and need 24/7 care for their daughter.

Jacqueline Fenton has two adult children with intellectual disabilities. The older of the two, Amy, has occasionally violent episodes and acts out, posing a danger to her brother and mother. There are no supports available for Amy, so Amy will join the ranks of the homeless because it is just too dangerous to keep Amy in the home. Amy is not a criminal, she is a human being with a disability; she needs to be provided with the stability that will give her an opportunity to find happiness in her life.

Numbers from *Pressures and Priorities* for the South East Region show a trend of deficits; as of January 25, 2008:

- 234 people are on wait list for residential services such as group home and supported living
- 273 people are on wait lists for program services such as respite care, therapy, clinical assessment, behaviour management and similar services;
- Of those 273 people, 134 are children;
- 142 people are on wait lists for day program support services

**SOLUTION:** The funding models needs to be revised. The current methodology, described by MCSS officials at the meeting, does not take into account the difference in cost and availability of supports and services in rural and urban centres, the difference in demand caused by differing levels of ability and needs with each individual.

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## Red Tape

Many individuals suffer from a loss of service due to administrative failures, and most of these failures are from a complicated and cumbersome delivery process that has too many different government agencies involved.

Ryan Whyte lives in Lanark, Ontario with his family and has Duchene's Muscular Dystrophy. The Champlain Community Access Centre (CAC) has the funding to provide Ryan with the services he requires but does not have the staff to provide the services. Lanark Community Planning (LCP) can provide Ryan with the services he need through a qualified third party care giver, has the authority to funnel the money to the third party care giver. The problem is the Champlain CAC will not transfer the money to LCP citing administrative and regulatory restrictions.

**SOLUTION:** From the moment an individual is diagnosed, the Ministry of Community and Social Services has to take responsibility for that individual's needs. **Families need one service window for all of their requirements, not the multi-jurisdictional nightmare that they currently have to deal with.**

## "Transition Age" Inequities

There is significant inconsistency when addressing the needs of individuals at "transition age". This is when they leave the education system at age 18 and into the community. People with disabilities who were wards of the state during their youth have almost unlimited access to funding when they reach adulthood. People who were in the care of their families (at significant savings to the province) have almost no access to assistance beyond basic ODSP.

In Frontenac County we have a 19 year old young man who will be homeless because ongoing funding from MCSS has not been secured to pay for his current stay at a high intensity group home outside Sharbot Lake. This young man has been presented repeatedly at the *Pressures and Priorities* planning table and repeatedly been told there are no funds available. He requires 24/7 care and there is no funding available to provide that care, so as of April 1, he will be homeless, despite the best efforts of local agencies and advocacy groups to cobble together enough funds to assist him.

I mentioned Karen York and her son Justin in the section on "Program Inefficiencies" well she is also an example of these "Transition Age" inequities. Had her son been put into the care of CAS when he was diagnosed almost two decades ago, he would have access to almost unlimited funding today; instead, she struggles to get the support he needs.

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Olga Travis is in her eighties. Her son, John is in his forties. When Olga is no longer able to care for John, who requires 24/7 attention, there is no place for him to go. He needs a group home, as supported living is just not adequate to meet his needs- but there are no group home spaces available, only waiting lists. Had Olga put her son into the system when he was first diagnosed, he would have been provided for all his life. Olga chose to provide care for her son herself in his younger years, and as a result could not get the level of funding she required when he reached transition age; she had become one of the “invisible” families- getting her son on a waiting list for a group home space becomes difficult, because so many “system” families are ahead of her. As she ages, she faces growing concern as to who will care for her boy after she is gone.

**SOLUTION:** Again, from the moment an individual is diagnosed, the Ministry of Community and Social Services has to take responsibility for that individual's needs. The system has to acknowledge the families who have chosen to bear the bulk of the responsibility in caring for their disabled loved ones and not be setting up discriminatory barriers and unnecessary hurdles for them when they need assistance. As intellectually disabled people often move from one level of care to another, one program to another and one specialist to another throughout their lifetime, the funding for these folks has to be attached to the individual and follow them through life; once again, families should not have to reapply to various ministries and agencies to find out if they qualify for one area of support or another.

## **Summary**

It is clear from what we heard at the “Being Mindful of Intellectual Disabilities Forum” that there are a number of inadequacies with the current program delivery and funding models.

**Shifting the funding model from a per-capita methodology to one that reflects the true nature of needs,** such as the *Pressures and Priorities* evaluations, as well as attaching funding to the individual where necessary, will go a long way to ensuring that the funds already allocated to this area are used more effectively.

The delivery model must become more efficient. Asking families to go *cap in hand* to multiple ministries and agencies asking for assistance is, put quite simply, unacceptable. **There needs to be one service window, one Ministry that takes responsibility for providing the necessary supports and services for these vulnerable individuals,** and the Ministry of Community and Social Services is best suited.

Once again, these families have spoken; they need to know they have finally been heard.

**31 March 2008**

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