

Family Alliance Ontario delegation met with The Honourable Madeleine Meilleur, Minister of Community and Social Services, Nov. 17 2010.

Barbara McCormack (President), Joyce Balaz, Christy Barber, Bill Hiltz, and Cindy Mitchell attended. Carol Latimer (Director, Community and Developmental Services, Valerie Picher (Minister's Chief of Staff), and Adam Nowina (Special Assistant-Policy) represented MCSS.

Barbara thanked the Minister for agreeing to meet with us and referred to the *Priorities for Change* document submitted in preparation for the meeting, Barbara began by speaking about the woefully underfunded Passports and SSAH programs, and about the slow pace that Transformation has taken. Barbara spoke of the many families who have no supports for their loved ones and how the burden is unacceptable when promises were so high. She asked for further information on how the system is going to be 'transformed' as there is no information in the public domain on how funding shifts will actually take place and we have been told that all current arrangements will be grand-fathered so as not to destabilize the system. It looks as if the only chance to shift dollars from agency services to direct funding will be when people pass away.

The Minister thanked us the parents for all the advocacy that we do and for taking such an active role in the lives of our sons and daughters. She is very appreciative of all the work that we do. The Minister spoke about how things have changed over the years and that children who went through the school system want to continue to be participants in their community. She spoke of the closing of the institutions and how people were transitioned into group homes and how some parents were against that move. She spoke of how every individual who is eligible for developmental services does receive ODSP.

The Minister highlighted the fact that Passports is a program that this government started when it took office. The problem was that it was started without prior assessment of the need that existed. The objective was to eliminate the waiting lists but instead the waiting list has increased. 3500 individuals (approx) receive Passport funding. She spoke of the need to support those individuals who are not receiving funding of any sort to provide for the inequity that exists. She spoke of how the individuals who have good advocates get more \$\$\$ than those who do not. It is her responsibility to try to make the system more equitable which is the reason for the application entities so that everyone will be assessed as to their need.

She recognizes that there is not enough money in the system to assist everyone who needs support, but that she is always asking for more money to help people.

There are 40,000 people with developmental disabilities in Ontario. Currently 15,000 of those people are being served. The Passport funding was implemented to provide for respite for families to get a break.

In answer to the question about transforming the system, the Minister spoke of how agencies are being asked to review the supports that would enable some people to require less support and perhaps move forward into semi-independent living situations.

Barbara spoke of the fact that historically support resources such as Passport are seen as a one-way charitable enterprise when in fact they are not. Direct funding resources are used to employ workers to provide supports which enable family members to go back into the work force and for people with developmental disabilities to reduce their dependence on ODSP by having supported

paid employment and thereby all contribute to the economy. In fact, many of the dollars given to the Passport program are immediately returned to the government in taxes. The Minister commented that Barbara made a good point.

Christy reinforced the need for individuals who are receiving service from agencies to have individual budgets identifying the resources committed to their support. This is critical to accountability for the funds allocated to service providers. This would also provide for true portability. Also, this would free more support dollars for direct funding arrangements.

Barbara added that agency services consume significant infrastructure and bureaucratic dollars and the better approach is to get the support right to the people who need it.

Bill commented that people need friends and that to meet friends, you need to meet people.

The discussion turned to the use of restraints. Cindy spoke of the unnecessary misuse of funding to train **all** agency staff members in the use of restraints and how the use of restraints perpetuates the myth that all people with developmental disabilities are people who are violent and could erupt at any time. She commented that many times persons are trained only to have the agencies provide un-training.

Here the Minister turned to her experience in the health care field and how it is common practice for restraints to be used in the hospitals and long term care facilities and the need for everyone to be trained in the proper use of restraints for the safety of the individual and workers. She spoke of one example where an elderly person was disoriented by medication and needed restraints and how the family was not informed prior and even though they were close by, there were not consulted and given the opportunity to provide support so that restraints were not needed. She said that there was a need for a system to be implemented whereby the use of restraints was regulated to avoid any future deaths. The protocol is clear. This measure was deemed necessary through the consultation of various behavior management experts.

Joyce commented that the training will only increase the use of restraints as it is seen as a perfectly acceptable thing to do. Here the Minister said that she would agree to disagree on the subject which ended the conversation.

The Minister referred to another incident where one mother was so shamed after having a child with a developmental disability that she shut the individual up into a cave and never acknowledged that she existed. The Minister commented that we have come a long way since then and that it will take time for the new system to take hold.

Barbara rejoined that while that particular situation has hopefully changed, the fact that our children and loved ones are currently stuck in their homes watching TV for want of any support dollars is not dissimilar from being shut in a cave – albeit that this cave is more modern and has a TV.

Minister Meilleur thanked the group for coming to meet with her and to bring the family perspective to her. She congratulated us on the work that is being done to help families. She suggested that families engage in the Finance Committee Pre Budget Consultations early in the New Year to advocate for more money to be put into the Developmental Services.

Carol Latimer thanked us for having a respectful conversation with the Minister and also suggested we make sure our voices are heard at Pre Budget consultations in the New Year.

Edited from notes recorded by Joyce Balaz