

Toronto Family Network
families helping families...
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Monday, February 5, 2007

Hon. Dalton McGuinty
Premier of Ontario
Legislative Building, Room 281
Queen's Park
Toronto, ON
M7A 1A1

Dear Mr. McGuinty:

We are writing to continue to express the shock and outrage of our families at your government's MCSS and MOHLTC July 2006 joint protocol called the Long Term Care Home Access Protocol For Adults With A Developmental Disability. On November 20, 2006, the Toronto Family Network wrote to the Minister of Community and Social Services, Madeleine Meilleur, and the Ministry of Health and Long-Term Care, George Smitherman, regarding this document. Below is the letter sent to both Ministers:

"I am writing as Coordinator of the Toronto Family Network to express strong concerns and questions regarding the MCSS and MOHLTC Home Access Protocol For Adults With A Developmental Disability ... The purpose of this email is to raise what we consider to be key issues, not to respond to each and every one of the 21 pages of the document. There is no time to do this effectively.

Our families within the Toronto Family Network are appalled, aghast and disappointed at the government's "Access Protocol" document which erroneously equates "community living" with placement in a long term care institution for adults with a developmental disability.

This new government direction is a surprise and extremely disconcerting to the tens of thousands of taxpaying families and individuals within grassroots organizations, such as Family Alliance Ontario, the Individualized Funding Coalition for Ontario, People First of Ontario, local regional family networks like our own, the Toronto Family Network, the Special Services At Home Provincial Coalition, etc. SSAHPC alone consists of at least 13 member organizations with special services at home funding being used by more than 20,000 Ontario families. FAO consists of more than a dozen regional family networks across the province. Community Living Ontario has expressed concerns about this "Protocol" document. Etc.

This "Protocol" does not at all represent "equity" and "inclusion" as suggested. Transfer to a nursing home facility cannot automatically be considered or assumed to be "safe, secure and

comfortable." We already know from countless reports and exposes that the long term care facilities within our province are fraught with problems of abuse and neglect. To backfill vacant nursing home beds for for-profit operators with adults with a developmental disability is serious step backwards and one which must be stopped.

The new direction reflected in the "Protocol" document produced by these two ministries represents a huge regression in public policy for the most vulnerable people within our society. The Toronto Family Network is writing as expeditiously as possible to express strong concerns and ask questions about the document and the process (or lack thereof) used by the ministries to reach this point in time and to produce such a terrifying document.

Our families found out about this "Access Protocol" in a Letter to the Editor in a local Toronto newspaper a few weeks ago about the existence of a July 2006 "Protocol" joint document. Until this point, families, networks, etc., had no idea of said document. When it was realized that this document existed in its current state, everyone was taken by surprise...followed by shock, then outrage.

To further learn that the Ontario Partnership on Aging and Developmental Disabilities report entitled "Building A Future Where Aging is OK" may have laid the groundwork for this "Access Protocol" document is even more disconcerting to individuals, families and groups who/that thought they have been collaborating in good faith with government bodies through consultation after consultation, year after year, opening up their lives and sharing their stories and fears in the hope that community inclusion --true inclusion not "integration" -- would become real and meaningful for more individuals with additional needs in this province.

Families were trusting when Government promised to close down the last remaining institutions for adults with a developmental disability. It would appear now that this government is opening the door to move disabled adults from one institutional setting to another institutional setting. The "Protocol" document appears to legitimize these kinds of placements --placements which have to do more with "residences" than "homes," more with "clients" than "loved ones," more with "services" than "relationships," etc.

The Toronto Family Network in the past several years has spent countless hours preparing for and attending a myriad of ministry-run workshops and public consultations in an attempt to help government understand the importance of self-determinization, citizenship rights, individualized funding and supports and inclusive communities. This year alone, TFN participated, on a volunteer basis, in the MCSS Funding Reform Workshop for developmental services, the Ministry's respite services review, the Ministry's "Opportunities and Action" DS Transformation Consultation, the Toronto Developmental Services "Vision and Alignment" Discussion paper consultation, the Ministry's Policy Forum on Quality Assurance, attended the Toronto DS Information Fair and has provided feedback concerning various ministry publications including the recently announced "Connections-A guide to transition planning for parents of children with a developmental disability." Toronto Family Network has also actively participated over the past several years in the MCSS's Special Services At Home Toronto Family Advisory Committee and other SSAH program initiatives to help improve understanding that

Ontario's developmental services budget must support community innovation and have a better balance between SSAH funding and programs (such as group homes and other services that are so much more costly). TFN has also extensively participated in initiatives of other ministries-- education, health, attorney-general -- as well as has worked directly with school boards, the Ontario Human Rights Commission, the Ontario Ombudsman Office, the Ontario Privacy Commission Office, etc. Suffice to say, after participating on a volunteer basis in so many governmental and non-governmental activities to represent families, one has to wonder if it's all been worthwhile? Has it made a real difference? All the hours and quality time we spent away from our children to participate and give feedback in so many consultations, etc., is now questionable --all because of this "Protocol" document that MCSS and Ministry of Health LTC have developed in secrecy-it would appear.

Four organizations mentioned above (IFCO, FAO, People First of Ontario and SSAHPC) spent a huge number of hours together over several months preparing an insightful 2-part document called "Common Vision for Real Transformation" of developmental services in Ontario (available online) that laid out in plain language and with specificity how individuals, parents, families and provincial as well as local organizations support the self-determination of persons with disabilities. The IFCO comprehensive study on the role of individualized funding and supports in Ontario ("Moving Toward Citizenship" dated April 2006 available at their website) made it clear that Ontario must develop a system of funding whereby the person requiring assistance, supported as appropriate by family and/or significant others, has access to and control over the funds allocated for his or her supports to give control over decisions concerning where they live, with whom they live, with whom they spend time and how they spend their lives. All this information, and much more, has been made at the ministry's disposal. It has not been kept hidden.

To learn recently that the Ontario Partnership on Aging and Developmental Disabilities" (OPADD) report "Building A Future Where Aging is OK" may have laid the groundwork for the Protocol document is shocking, quite frankly. We understand that OPADD membership on the Ontario Partnership on Aging and Developmental Disabilities includes Reena, Ontario Agencies Supporting Individuals with Special Needs (OASIS), the Ontario Association of Non-Profit Homes and Services for Seniors (OANHSS), the Ontario Gerontology Association (OGA), and the Ontario Long-Term Care Association (OLTCA). No FAO. No SSAHPC. No IFCO. No OACL I believe, which often has the minister's ear. And most disconcerting, no People First of Ontario.

Where has been the transparency and accountability throughout all of this?

How can it be possible that the very groups that consist of the key stakeholders i.e. individual families, parents, self-advocates, be unaware until now of the "Access Protocol" document? How can it be possible that key provincial organizations like IFCO, FAO, SSAHPC and People First had no idea of this "Protocol" until it was mentioned in a local daily in a letters section? Could this process happen to people with a developmental disability without their families' full understanding and agreement? Would this not possibly be a violation of the Nursing Homes Act, the Ontario Human Rights Act, etc?

How can members of the public feel they have a relationship of trust with the Government in power and feel participation in government consultation processes are worthwhile if ministry documents such as this "Access Protocol" exist without having been put through a proper public consultation process?

Immediately withdraw the MCSS and MOHLTC "Access Protocol For Adults With A Developmental Disability." Please stop placing (or considering to place) people with a developmental disability into these facilities and rather, offer the option to move people who have been placed there back to the community into a place that can be a home, with the appropriate individualized supports developed through careful independent facilitative planning coupled with the direct funding they require to successfully carry out said plan. Our society needs more community capacity, rather than a continuation of the warehousing mentality. If the Ontario Government is to have a chance to regain the trust of thousands of voters, then the "Protocol" document must be recognized as draconian and regressive and it must end immediately. Tens of thousands of citizens in this province can't be wrong."

In her letter of December 19, 2006, to the Toronto Family Network, Minister Meilleur stated that "The protocol did not convey a new direction, but clarifies roles and responsibilities for the long-term care home placement planning process that already existed in the province". To be informed that the protocol does not convey a "new direction" raises many serious questions that need to be addressed by the Premier's Office. The Minister's letter also states that the protocol document "provides clarity to relevant transfer payment agencies and other service providers in support of transitioning adults with a developmental disability to the long-term care home sector". If this is the case, where and when and by whom is "clarity" being given to the key stakeholders, people with a disability and their families? There is a website from New York State. It includes a document that shows that children and youth are being placed in long-term care facilities as well as individuals with a range of disabilities under the age of 60. Is this where the Ontario government got the idea for their protocol document?

To convey the urgency and seriousness of this extremely harmful protocol, below is the letter written recently by the Toronto Family Network to the Toronto Star:

"Re "Bill will cut care for seniors: Critics" (Jan 17) by Queen's Park Bureau Reporter Kerry Gillespie: If passed, Gillespie writes that Bill 140 will replace older legislation affecting 75,000 residents living in long term care (LTC) facilities. Critics of Bill 140 believe that the legislation does not include minimum hours of care, something that the Liberals promised to introduce during the last election campaign.

While talking about Liberal broken promises, let's not forget how the Ontario government is horribly failing Ontario families and their loved one with a developmental disability concerning another pressing LTC-related matter. The very sad fact is that the government is encouraging and facilitating the placement of people with developmental disabilities, including adults as young as 18, in long term care institutions in this province.

The 21-page joint "MCSS and MOHLTC Home Access Protocol For Adults With A Developmental Disability: (July 2006) is appalling, disappointing and demeaning to many of those directly affected. Public outcry concerning this Access Protocol was raised in the Ontario Legislature by MPP Shelley Martel before the holidays.

The McGuinty government is unnecessarily institutionalizing sons, daughters, brothers and sisters with a disability in nursing homes at the same time as it is taking credit for deinstitutionalizing regional facilities for the disabled.

Had the Ministry of Community and Social Services not turned down families for Individualized Funding and Supports ("Direct Funding"), loved ones wouldn't be wasting away in long term care facilities, which is indeed the case in this province for thousands. They belong in their own homes, not a long term care facilities pretending to be home-like, and do not have adequate quality care standards.

The Access Protocol does not at all represent equity and inclusion, as suggested in government rhetoric. The Toronto Family Network along with other grassroots organizations that include self-advocates, parents, association members, etc. have spoken out stating that the Protocol document erroneously equates "community living" with placement in a LTC institution.

For government to consider that nursing homes are part of a continuum of "community-based care" is so far from the truth and dangerous, according to thousands of taxpaying families represented by provincial organizations such as Family Alliance Ontario, Community Living Ontario, People First of Ontario, the Individualized Funding Coalition for Ontario, Special Services at Home Provincial Coalition, etc.

For families and groups to discover by accident in a newspaper letter to the editor last Fall that there are detailed plans forcing people with various disabilities into nursing homes has been extremely overwhelming, shocking and disconcerting. There has been more than 2 years of public "consultation" by MCSS on the transformation of the developmental services sector but never was there information shared about backfilling nursing home beds with young people with additional needs. Families and individuals representing community groups have spent countless hours preparing for and attending a myriad of government consultations/meetings to raise the awareness and understanding of the importance of self-determination, citizenship rights, individualized funding and supports, choice and control, and inclusive communities. For years, the public and government have agreed on the necessity for greater interministerial commitment, co-operation and joint initiatives, but never ever did families and groups expect ministries working together to produce such a shocking document as we have before us. To learn that an Ontario Partnership on Aging and Developmental Disabilities report may have helped lay the groundwork for this Protocol is even more worrisome.

Families were trusting when there were promises and steps taken to close down the last remaining regional institutions for adults with a developmental disability. Now we know that the government is opening the door to move disabled adults from one institutional setting into

another. Where is the transparency and accountability through all this? How can the key stakeholders be unaware only until recently that the Protocol document, and others dug up, exist?

The Protocol must be withdrawn immediately. The Ministers and their staff have been sent letters about this and they have heard this repeatedly from families face-to-face during Ontario developmental service consultation focus groups held as recently as December and January. Abolish the Protocol and re-allocate funding from the institutional setting to families in ways that allow for individualized supports developed through independent facilitative planning and with appropriate amounts of individualized dollars that are required to successfully carry out their plan, continuously review it and, if needed, update it. (For those people who may be concerned that this may be more costly, it's actually not.)

Society needs more community capacity and creative approaches, rather than a continuation of the warehousing mentality. If this Ontario Government is to have any chance of regaining the trust of the voting public, then clearly the LTC Access Protocol must be recognized as draconian and regressive and must end. It's time to stop this secrecy and follow the recommendations from families across Ontario.

Let's bring sensitivity, respect, dignity and transparency to the forefront of planning and decision-making about the lives of the most vulnerable citizens in our province. They deserve no less, wouldn't you agree? “

Further to these letters, the Toronto Family Network has learned about the preventable tragedy of two men, Mr. Croteau and Mr. Belliveau, who have developmental disabilities, are under age 65 and living in a long term care facilities. Clearly there is a need for the Ontario Ombudsman to investigate this tragedy and the access protocol and other related documents as they have a far-reaching and harmful impact on the most vulnerable citizens of this province.

Premier, your leadership is key at this time. Families and their loved ones with additional needs are counting on you to take immediate action.

Sincerely yours,

Janis Jaffe-White
Coordinator

Copy: Hon. Madeleine Meilleur
Hon. George Smitherman
Mr. André Marin, Ontario Ombudsman
Ms Shelley Martel, MPP Critic for Health and Long-Term Care
Mr. John Tory, Leader PC Party