



Family Alliance Ontario

representing people with disabilities, their families, and their friends

December 5, 2011

The Honourable John Milloy MPP
Minister of Community and Social Services
80 Grosvenor St
Hepburn Block
6th Floor
Toronto ON M7A 1E9

Dear Minister Milloy,

Congratulations on your appointment as the Minister of Community and Social Services. We hope that we will be able to meet with you in the near future to discuss our organization and update you regarding the needs of thousands of families across the province who are struggling to meet the needs of their sons and daughters and loved ones with developmental disabilities.

Family Alliance Ontario is the representative board of 14 Family Network groups throughout the province stretching from Windsor to Ottawa. We have participated at the Partnership Table for the Transformation of Developmental Services since its inception and represent the family voice in many forums and committees.

It is the Transformation process that we would like to discuss with you as we have many questions about what this process really is and where it is headed. After more than 6 years of effort, there has been little or no benefit for the majority of families outside the agency support system, and there are no promises and commitments in the future.

As a result of these frustrations, we ask you to kindly respond to the following questions:

- We have not been privy to any documents describing what a transformed developmental services system actually looks like. Could you describe to us your vision of what a transformed system looks like across the sector? How will we, or anyone else, know when the system is considered successfully transformed?
- Assuming the current activities are part of a process leading towards a conclusion, could you please describe the future processes that will enable DS to reach its goals, as they pertain to families?
- What is a realistic timeframe for this effort? Our families languish on 'waiting lists' for years and see no end in sight. These waiting lists are not managed where one can climb to the top, and the process of dealing with them is not transparent, equitable or fair. In reality, do our families have any hope, **ever**, of receiving support?
- At the beginning of the Transformation process in 2004, DS funding was split 93% to Agency support and 7% to direct funding for individuals – despite the fact that a similar number of people were supported by each category! Does a plan exist that describes how and when families will receive equitable supports and services across the province, irrespective of whether they are served by agencies?

We do understand and acknowledge that building blocks are being put in place for a potentially new policy approach. So far we have seen:

- The development and proclamation of the Social Inclusion Act
- The establishment of Developmental Services Offices
- The introduction of the SIS assessment protocol

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- The introduction of Transition Planning policy
- The outline of an HR Development Policy
- Policies regarding the use of restraints and a complaints policy
- The planned realignment of SSAH for adults to the Passport program

However, important though these may be in legislative terms, **none of them actually helps families at this time or offers any guarantee of support for families in the future.** Many of these policies and activities appear to be created in a vacuum and risk being worth only their paper.

For example:

- Families are subjected to hours of interviews for the SIS assessment, which is promoted as offering new ideas, new ways of looking at things, employment possibilities etc. only to find that no funding is available to support those ideas and they will need to join a so-called waiting list.
- Similarly, the Transition Planning initiative (which, incidentally, appears to involve only agencies with no mention of direct funding or alternate lives in the community) is not attached to any defined funding. The young person will leave school with a viable, progressive plan in place only to join another 'waiting list' and languish at home.
- The HR policy has been developed in a vacuum from the very substance of Transformation. After three years of meetings, consulting groups, marketing agencies and considerable time and expenditure, it appears no thought or value was given to the needs of families employing staff in a direct funding arrangement, or the supports required by families to manage staff, or the needs of workers in this sector. This oversight is extraordinary given that 165 agencies and the Ministry were included in the process. We believe that this policy would be better named as a Developmental Service Worker strategy for agencies.
- SSAH funding for adults is being rolled into Passport with no examination of the many challenges that currently exist in the under-funded Passport program, its lack of transparency, fairness, accountability or viable appeal process. This is causing an outcry among families who see the future lives of their loved ones subjected to the unaccountable decisions of an unknown group of people in an arm's length transfer payment agency.
- The DSOs have already turned away many individuals with IQs greater than 70, despite their needs for adaptive functioning. This is an incorrect application of policy and an illustration that the DSOs may not clearly understand their responsibilities.

Like many organizations, including our Common Vision partners (Special Services At Home Provincial Coalition, Individualized Funding Coalition and People First) we had great hopes that Transformation actually meant a **comprehensive change in the delivery of developmental supports and services.** We believed that the government wholeheartedly supported the aspirations of people with disabilities to lead included, valuable lives in the community, rather than in segregated settings.



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Given that a real system transformation requires substantial commitment to action, we would like to ask if any requests have been made of the agency sector to release their stronghold on a vast percentage of DS funding to help support Transformation's goals?

Are you able to share with us:

- What efforts have been made by DS to help the agency sector become more efficient so that money can be reallocated to the thousands on waiting lists?
- Have any efforts been made to encourage agencies to share resources? Do we really need over 200 agencies in Ontario with their own CEO's, infrastructure, operating costs and so forth? Could some of them be encouraged to merge or share services/locations/staff, to release funds to help achieve a real Transformation?
- Have any individuals living in agency supported group homes been offered an individualized funding package with the opportunity to live in different, less expensive, more inclusive arrangements? – Could funds be released from an initiative like this to meet the critical needs of another person?
- Have agencies been encouraged to consider how they can support or offer services to direct-funded families, such as has already happened in more forward-thinking jurisdictions around the globe.
- Under a transformed system, will individuals with the same score on their SIS assessments receive the same level of support? In other words, will agency-supported individuals be grandfathered into new arrangements at the current funding levels - or will agencies and families receive the **same support dollars per individual** – as assessed - according to a funding model (notwithstanding agency overheads and accommodation costs)?

In summary, as you can see we have many questions concerning the transformation of Developmental Services. We are frustrated by the slowness of the process, lack of clear direction and uncomfortable feeling that this is not really a Transformation at all. We do not see any clear commitment from the government to support the thousands of families currently 'out' of the system. To us, it appears that vast sums of money are being spent and time wasted on committees and consultants, meetings and advisors in a journey towards something that will mean **no change** for the thousands who wait. It is our families who are paying the heavy price of under-funded supports and services, our sons and daughters who cannot lead fulfilling lives, while this process limps along to its unknown destination.

The slow pace of change puts Ontario at the lower end of the spectrum compared to other advanced jurisdictions in terms of respect, support and willingness to include people with disabilities in the community to enjoy their rightful place as citizens – despite Ontario's commitment to do otherwise by the ratification of the UN Charter on the Rights of People with Disabilities. It is tragic that support for the most vulnerable citizens of this province is considered discretionary with waiting lists enshrined in law.

We would very like to meet with you to discuss these serious concerns and hope that you may have some time available for us in the New Year.

Sincerely

Barbara McCormack,

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