



Family Alliance Ontario

representing people with disabilities, their families, and their friends

Alex Bezzina
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Dear Alex,

I'm not sure whether you remember me from our meeting with Minister Meilleur while you were at MCSS. I remain President of Family Alliance Ontario and continue to care for my daughter Sarah at home. I wondered if you could provide me some guidance as to who we might speak to on some different, health-related issues. These issues were raised at our recent annual strategy meeting regarding many of us who have children with both developmental disabilities and complex medical needs:

1. CCAC support/nursing homes

CCAC support remains a massive challenge for our medically complex children, especially as they reach adulthood. Families are told that if they need support beyond the hours allocated – and this is inevitable for children who require round the clock care – then their children must be institutionalized in Complex Care settings despite the enormous additional cost. CCACs insist on this step because they have no scope within their guidelines to provide more hours (or individualized funding arrangements) and complex care centre/nursing home, although more expensive, are “on a different budget”. This is causing immense distress among families whose children are being forced into these homes when it is far less costly and more desirable to keep the person at home and in the community.

2. Inter-RAI Assessment Tool

Many of our family members are currently being assessed by their local CCACs with the Inter-Rai assessment tool designed for seniors with dementia. This process is showing some alarming issues where the assessment tool looks for deterioration and cannot take account of a starting point of complete helplessness. Families have been told that they may lose their support if the results of the assessment are applied. Why is such an inappropriate tool being used with this population?

3. Family Health

Many of our families are now seniors supporting adult children and their own health conditions are at risk. We have heard dreadful stories of parents with cancer, or becoming frail from surgeries or broken limbs and finding nothing in place, anywhere, to provide extra support through their crises and recovery time. Caregiver burnout and mental health challenges are growing as parents grow weary of their obligations to their children from having so little support.



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4. Medical support after childhood

Our families report on the impossibility of finding family medical practitioners who are comfortable dealing with the complex medical issues of adults with developmental disabilities. The infrastructure in place during childhood suddenly disappears and there is nothing to take its place, nor is there any transitional help to guide families. They are simply dropped as soon as their child reaches their late teens.

*I won't go on, but this gives you some ideas of the challenges families wish to discuss. The bottom line is that there is no system in place designed for the small percentage of children with profound medical needs and developmental disabilities as they grow through childhood into adulthood. Instead they are fitted into programs designed for other populations that offer little support or appropriate infrastructure. That being said, we believe a better system can be developed that will help families more **at less cost to the government.***

We would much appreciate the opportunity to discuss our challenges and concerns with MOHLTC and wondered if you might direct us accordingly. I do not believe that the Minister has ever heard from our group and if there was such an opportunity, it would be much appreciated.

Best regards

Barbara McCormack

President

Family Alliance Ontario

www.family-alliance.com