

I am Marcel Walsh and I am here today as my sister, who is in her mid 40's, is multiply handicapped. This bill and how it is implemented will directly impact on my sister, my mother and on my life.

My sister has always lived at home and is cared for on a day to day basis by my Mother. My parents a long time ago decided they wanted to keep her at home with them and be cared for by them. My mother now provides all the care but her health is failing and she is aging. I am the only other family member who lives close enough to provide some support for my mother. My Mother's whole life has been caring for my sister and it will continue to be until she passes away.

As my other family members are spread out with their own families and they have expressed clearly they will not be assuming the care of my sister when our mother passes. I will need to make important decisions on behalf of my sister. What ever plan is put in place it will mean big changes in her life.

When my mother is no longer able to care for her it would be important to move her into a setting, her own home as she ages. As few transitions as possible is important to her well being. I certainly am not in a position to provide the high intensity 24 hour care she needs. Nor would she be comfortable having her brother bath her and take care of her other very personal care. Also we will be growing old together. She will need a residential placement were her needs can be met. I will always be involved but she will need the support of a community living agency --- that is healthy and well resourced. Before moving into a residential home I anticipate a transition period where she will need support in order for her to stay as long as possible in her and my mothers home.

I am here because I am looking at my sister's future.

I believe all people --- including my sister --- are citizens of this country and province and should be entitled to the care and support they need to be safe, secure and able to participate in community life as fully as possible. This requires good solid supports. It needs legislation that commits this level of supports as a right and that people are not put on waiting listing depending of how much monies are in any particular geographic area. There should be clear commitment of the government that these services will be provided to those who need them.

I began to work in the developmental services field when I was 16 years old. Although I went to school to get my masters in psychology and did my nursing degree it was not long before I came back to working in the development service sector. It is where my heart is. I have worked in 3 provinces. Nova Scotia, Alberta and Ontario. Of the 3 provinces I believe Ontario, even with all its challenges, provides the best care. I believe however this legislation is moving us in the absolutely wrong direction.

I want to tell a story from my Alberta experience. I was hired by an agency to work 9 to 5, Monday to Friday in a family's home. The family needed to take out extra insurance to cover their liability as the son I was working with had high behavioral needs. The parents had a falling out with the agency and fired them but asked me to continue. They had "choice" so they decided to move their pot of money to another agency that had just been established. I was committed to this family so I stayed. They transferred their contract to the new agency. They bounced two of my pay cheques so the family moved to directly funding my position without agency support. They had their own resources to top up my pay cheques but still I had no benefits. I had no supervisory supports and they had no coverage if I was sick. When I sustained a serious injury from a behavior incident the family paid me but needed to hire someone to cover for me while I was off recovering for 6 weeks. I realized if I was hurt again they could not afford to pay me again. I

realized how vulnerable I was and how isolated I was. I did not even have co-workers or supervisory supports to assist in developing new strategies to deal with the behavioral issues. I had to make the difficult decision to leave. These were great people. But I had no ongoing training, no accountability except with the parents whose perspective was limited to their own experience and no protection if I was injured. I still keep in touch with the family. They are truly wonderful people. Parents who under individualized funding ended up placing their son in an already existing agency as they realized that they could not do it on their own. I worked in their home for a year – after that it was a revolving door with big gaps where they had no one to provide support. This story repeats itself many times. It does not work having a pool of workers floating out there providing service without ties to an agency. It does not provide good supports.

The government says this is about choice. My wanting the best for my sister is not a choice. It is an expectation. She deserves it. It should be her right. Developing a system that does not have the same accountability for everyone who work in it is not the best for my sister. Having community living agencies struggling to keep staff is not good for my sister either.

What is best for my sister is a system that ensures dignity and respect and that planning and services are delivered in a thoughtful, caring and well resourced way. Choice for my sister is being able to access service to keep her at home as long as possible and then moving into a residual program when it becomes time. Choice is about having the types of supports that fit her needs as they evolve. It is not about whether I get to manage the money or not.

I strongly urge the government to put language into the act that commits the government to providing the services to people supported by services in this sector. Waiting lists for people is not the way to respond to need. I urge you not to go down this road of a floating pool of people providing support without the supports of an agency. I've been in both systems. The direct funding model has more downsides than ups.

Thank you for your consideration