

You are getting to the end of four very long days and we thank you for this opportunity to appear in front of you as one of the last presentations of this consultation process. My name is Connie Hurtubise and joining me is Amy Parker.

Let me start by saying that the government of Ontario's stated commitment to revitalize social services and to provide effective supports for vulnerable people in the province is so important. The social service field is the 3rd pillar along with the first two pillars education and health. So in the 2004 when the Government of announced that the province would be transforming supports for people who have a developmental disability to create a coordinated system of community-based supports that is accessible, fair and sustainable, there was huge hope that a long time neglected group within our province had become a higher priority on the government agenda.

Amy and I come here today, as front line workers in the developmental service sector – Amy from an agency in the Ottawa area and I'm from an agency in the Cornwall area. We are not here representing our employers. We thank you for the opportunity to participate in this consultation process.

The government has had lots of feedback, from various sources over the last number of years. Although there are clearly some differences there is a strong theme of problems related to access.

The goal articulated by government is making the system fair; making the system easier to use, more accessible; of having the opportunity to access funding, no matter where you live, and of having flexible funding which would allow for choice, so that decisions could be made for the appropriate supports and services for the individuals. It is what we all want for this sector

Amy and I work in this system and we have had the privilege of meeting, talking and working together with families and workers so we are not at all surprised by the findings of past consultations. Although we applaud that the government is taking the developmental services sector revitalization challenge on, we are discouraged with the direction of Bill 77.

A consistent message is that it is hard to access the current system, that there are not enough supports, not enough workers, insufficient wages to recruit and retain qualified workers; and all too often we find that there are families to this day still having very hard times. The 2006 report by Ernie Parson's also sets these very challenges out.

One of the main principles underlying the transformation of developmental services is that people who have a developmental disability are people first. It is therefore important we start there.

In May of 2006, the government suggested that a successful outcome of the transformation will be the extent to which people who have a developmental disability are recognized and valued as being part of the community. Our shared goal is to enable people to live in their communities as independently as possible and to participate as full citizens in all aspects of community life.

We believe strongly that this commitment must underpin the legislation. Our recommendation is to include a preamble to the Bill that acknowledges the inclusion of all residents as the foundation of a strong Ontario, including persons with a developmental disability. We believe that"Inclusion moves from being an ideal to becoming a reality when we acknowledge the entitlement of persons with a developmental disability to support services that are available consistently across the province and are based on person-centred planning." We agree.

Citizenship should serve as a benchmark for legislation as it will give clear value statements and guides for the development of regulations.

In order to meet our shared goal we believe the legislation must also guarantee access to service. A mandating of service is crucial in the support of individuals with developmental disabilities and their families. Families, agencies and workers are pushing hard for a system that is proactive and responsive. The reality is that resources have not been provided to do this in a way that fully responds to individual and family needs.

When you look at the length of waiting lists and the difficulty of access to supports and services to support individualized plans it really

comes down to creating an infrastructure to support the commitment of support and services. The response should not be legislation to manage waiting lists.

Amy will share an experience that highlights the need for accessible service..... [respite care experience]

Parents should not have to take this type of action to access service. This situation is not as uncommon as you would think. Families needing to access residential beds or independent living supports must often be in crisis before they move to the top of the list. This is heart breaking!

There has been lots of discussion around the concept of choice. Amy and I fully support the right to have choice, but where is the choice if you are sitting on a waiting list. Bill 77 has entrenched waiting lists right in. Where is the choice if a family must reach "crisis" in order to be bumped to the top of a priority list in order to receive services. It is more appropriate, caring and respectful to have a families involvement when implementing change for a family member, than to invoke change after the death, or breakdown of a parent, or caregiver.

Also access to support to keep people in the home or access to community programs is challenging. Funding and supports need to be innovative, and flexible. Individuals need to know that their access to services will change over time as there needs change.

Choice is not about a funding model. It is about individualized person centered planning, it is having quality mandated supports and services provided by qualified staff, who are supervised.

Too often Amy and I talk to families who have successfully received funding under the current individualized funding programs in order to support their family member, only to find they cannot find workers qualified, and willing to do the job. They must concern themselves with hiring, training, and managing staff. They must do without service when the workers they have hired are sick or injured. These situations fail to provide consistency for the vulnerable individuals that we strive to support.

There can be NO choice if the supports and services are not in place in the community to take an individual's plan; that person's and their family's hopes and dreams, and put them into action.

Individualized funding caters to a few. There is concern when the focus of this legislation seems to be an expansion of this funding rather than committing to a level of service and access. By far the greatest demand for services are for services delivered by community based agency programs. If the legislation ignores strengthening agencies, then it is a disservice to individuals with a developmental delay and their families.

Community agencies have a structure to insure staff are trained, supported, and held accountable for service delivery. Supports need to be equitable and people should receive quality mandated supports across the province. There needs to be a set standards of quality of service for all.

What good is recognizing the necessary supports and services that a particular individual and their family may require, if the community or surrounding area does not have that service? Does this piece of legislation have a plan for providing the necessary supports and services regardless of where you live in the province?

How can the goal of recognizing people who face the challenge of a developmental disability every day as "people first" be faced without a plan to ensure supports and services are mandated for all, and will be available regardless of geographical area, severity of disability, existing services, etc.. Does this Bill identify these questions?

Systems are put in place for a reason --- they are there to ensure consistency and quality. This legislation further fragments the sector -- if the focus of this legislation is about choice then create legislation that commits to mandated service and fund it so there is choice of appropriate quality accessible supports and services for individuals with developmental disabilities.

One final point is a concern about individuals needing to be diagnosed by the age of 18 in order to be covered by this act. This means individuals who are incorrectly diagnosed prior to the age of 18 would not be eligible for services and supports under this Act. This was likely an oversight and we urge the standing committee to recommend changes to ensure that this doesn't happen.

We thank the committee for hearing some of our concerns.