

Following are the responses from the Federation of Advocates for the Developmentally Disabled to the questions put forth in the Developmental Services Discussion Paper (2004 version):

Question One

The care of a population's mentally and physically vulnerable, such as the developmentally disabled, is an area where government's unique abilities and orientation work best.

Government needs to be accountable in the developmental services sector, because making available care and services to the weak and vulnerable is one of society's necessities. Citizens pay taxes so that government can meet society's necessities.

Service providers must deliver care and services that is appropriate to the level of disability of an individual. They must not overlook an individual's real-life needs in favour of propagating an ideology.

The role of business, faith-based communities and cultural organizations, service clubs and voluntary organizations is to provide ancillary supports. It is not appropriate to rely on these for capital and operational requirements.

Question Two

This question and the statement on page 8: "This vision affirms the importance of full participation in society for persons with disabilities," are reasonable and practicable for people whose disability is mild. However, it is of no value to people with profound, severe and/or multiple disabilities who are simply unable to participate. We must acknowledge this FACT and develop strategies and programs specifically for them.

The new dementia section at Rideau is an excellent example of how centres can tailor their services in a cost effective manner to the unique needs of the

growing segment of developmentally disabled with dementia.

Question Three

Comprehensive Care Centres, i.e., Huronia, Rideau and Southwestern, provide outstanding services for people with profound, severe and/or multiple developmental disabilities. They work well because they are able to

provide a secure environment on a 24-hour per day basis. They have well-trained, specialized and experienced staff. They have excellent facilities, including:

- new, modernized bedrooms, dining and living areas
- social, educational and recreational activities
- specialized medical, dental, psychological, psychiatric, dietary and physiotherapy services

Huronia's innovative McGhie Apartments are an excellent example of how centres have been retrofitted to reflect modern community living.

The advantages of appropriate, consistent and accessible care and services that centres demonstrate, need to be duplicated in other areas of the province where the need for residential supports is extreme.

Question Four

The level of individual funding should correspond to the person's level of disability.

Question Five

There is a need for 24-hour per day care for persons with profound, severe and multiple disabilities. These disabilities may result from a variety of problems from birth.

They may have serious behavioural problems:

- self-abusive and easily become agitated
- abusive towards others
- constantly search for cigarette butts or objects such as paper, clothing tags, etc. which they eat
- they rip up clothing
- flush items down the toilet
- throw temper-trantums
- smear feces on themselves and their surroundings

Many are unable to hear or speak and are unable to perform tasks related to their own hygiene such as bathing, tooth-brushing, shaving and hair-combing. They have no concept of risk or danger, therefore they must have a protective environment so that they will not endanger themselves or others.

There is a need for residential services that are tailored to these situations, just as there is a need to provide accommodation for those who have mild disabilities.

Therefore, the entire system of care and services should be seen as a CONTINUUM ranging from less-integrated-community-living, e.g., comprehensive care centres, to more-integrated-community-living, e.g., independent living options.

A developmentally disabled person's place on the continuum is based on their level of disability. A person with a severe disability is best served by a less integrated living option. A more integrated option would best serve the mildly disabled individual.

Question Six

#1. Create linkages to other ministries, such as Health and Long Term Care to address the often overlooked health priorities and issues of people with developmental disabilities.

#2. Make better use of current structures to deliver appropriate levels of care. Build new accommodation options with the same intent.

#3. Provide day supports (programs) to ensure that the developmentally disabled living with families or other settings are not isolated from their peers.

Question Seven

The Federation has been a recognized stakeholder in the developmental services sector for years, e.g., served on the Minister's Advisory Committee on Developmental Services, made presentations to Standing Committees. The Federation would like to know why it was excluded from the formulation of this discussion paper?

The Federation recommends that a thorough follow-up on former residents of Edgar and Midwestern needs to happen before major changes to the sector occur. This follow-up should be done by an unbiased third party.

It is time for us to abandon outdated and inaccurate language, such as de-institutionalization and the false dichotomy between community living and non-community living. The innovations that have taken place, and are taking place, at comprehensive care centres as well as the huge potential for additional enhancements make centres, what "Challenges and Opportunities 1987" referred to as, "core residential models."

Respectfully submitted by:

Federation of Advocates for the Developmentally Disabled

www.continuumofcare.ca

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