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Inclusion Comes of Age!

I would like to thank-you so much for this opportunity to share information on Aging and Developmental Disabilities to help inform the development of the new Seniors Strategy.

For the first time in history, people with developmental disabilities are living into older ages. This is due to medical advances and huge improvements of their quality of life with the closure of institutions. This success is to be celebrated and also provides a challenge to deal with the unknowns of the support needs of those aging with a developmental disability. We know that this population is highly vulnerable and can have complex support needs. With aging, this brings another layer of complexity as well as a new point of inclusion into society. Since individuals with developmental disabilities never before lived into older ages, the senior sectors is unaware of their needs and are not accustomed to their inclusion into their services and supports.

Individuals aging with a developmental disability have many similarities to the general population. All the various social and medical issues apply; however, they are increased due to their vulnerability. In addition, there are differences such as early aging. Evidence shows that those with any neurological conditions age at least 20 years earlier and with Down Syndrome, the average age of onset of Alzheimer's disease is 55 years old. A recent study (HCARD) showed that the frailty of a person at age 80 years is similar to those with developmental disabilities at age 50 years. This poses challenges for services that see "seniors" as a chronological age. Many individuals with developmental disabilities are denied access to programs since they are under the age 65 years at the time they require the supports. In fact for those with Down Syndrome, it is rare for anyone to live to the age of 65 years when they would be eligible. Another barrier to access services is the lack of openness to inclusion. As I mentioned that due to lack of exposure, many services for seniors lack awareness and knowledge of how to provide supports to those aging with a developmental disability. There is a need for the sectors to work together so that the person receives both the developmental as well as the supports in the seniors sector. Educational initiatives have helped this issue but need to expand and also include pilot initiatives to test models and demonstrate success – then share how this is possible to others.

Reena has taken a leadership position caring for seniors and opened the first seniors' home for those aging with developmental disabilities and been leading OPADD, the Ontario Partnership on Aging and Developmental Disabilities since 1999 (<http://www.reena.org/training/opadd/>). The vision of OPADD is "That older adults with a developmental disability have the same rights to support and services as all older Ontarians." Since 1999, Reena approached the aging issue from a principle of partnership. We felt that neither the developmental sector nor the health and seniors sector had the knowledge and skills to support people aging with a developmental

disability. We felt the answer belonged to both sectors working together and developing unique models, leveraging their strengths and co-creating strategies.

We have included two attachments.

The first attachment is a recent presentation on the various aging and developmental disability projects. It includes the below sections:

1. We want to thank MCCSS for a grant related to Aging and Developmental Disabilities. Included in this grant was a project on researching frailty and developmental disability. We developed an integrated care planning template and process to help improve and/or maintain the ability of people to remain in their community. The focus was on early planning and using resources from developmental services, health and seniors.
2. This grant also encompassed the development of “Aging with a Developmental Disability: Planning for Success” Guide.
3. OPADD supported MCCSS and the Ministry of Health in their development of “Guidelines for Supporting Adults with a Developmental Disability When Applying to, Moving into and Residing in a Long-Term Care Home”. We have been disseminating this information and challenging service providers to implement these important guidelines.
4. Reena along with partners in Manitoba and British Columbia are advocating for the inclusion of those with developmental disabilities into the National Dementia Strategy and the implementation plan. We were very pleased to see that our efforts did result in those with developmental disabilities being part of A Dementia Strategy for Canada: Together We Aspire. We are now advocating as part of the next steps of the strategy for specific projects around research and a National Dementia and Developmental Disabilities curriculum. Reena and our partners in Manitoba and British Columbia are part of the NTG-Canadian Consortium on Dementia and Developmental Disabilities. We have been collaborating with the National Task Group (NTG) in the U.S on a dementia curriculum adding Canadian content and enhancing the material with the plan to deliver this across Canada. Reena is the lead agency in co-ordination, registration and accounting of three pilot education sessions of this curriculum that occurred in the past year. We are now working with our U.S. partners on a long term collaborative agreement.
5. We have partnered with the Central LHIN, home and community care on many cross-sector initiatives for aging individuals with developmental disabilities. Some of these include; specialized community care coordinators, trained nurses in developmental disabilities, an occupational therapist and speech and language enhanced role initiative, behaviour therapy pilot and specialized convalescent care (to assist with those in hospital but not ready to go back home without additional rehabilitation)
6. Many thanks to the Ministry of Seniors and Accessibility for a grant last year that brought aging and developmental disability training across 10 areas of the province.

This training specifically was offered across sectors with the evening before to assist and support families. This was an extremely successful project with many requests for this to continue.

The second attachment is a fact sheet on the Ontario Partnership on Aging and Developmental Disabilities.

Some specific recommendations for the Ontario's Senior Strategy:

- a) To ensure that aging individuals with developmental disabilities are specifically named as a vulnerable population that requires special consideration.
- b) To note that some groups such as those with developmental disabilities may require services for seniors prior to the age of 65 years and that this should not be a barrier to inclusion.
- c) To state the principle of inclusion and that eligibility criterion for programs, services and supports should not be discriminatory due to a developmental disability. That adaption and partnership with the developmental services sector need to occur to set the stage for successful inclusion.
- d) Co-creating cross-sector innovative models should be encouraged through pilot programs with evaluation and dissemination of results.
- e) Cross-sector education and knowledge dissemination are key to broaden the awareness and expertise to support those aging with a developmental disability.

We are very open to meet with any staff from the Ministry of Seniors and Accessibility to discuss these projects and our suggestions for the strategy.

Sincerely,



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