

The Cerebral Palsy Association of Manitoba

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Ms. Joëlle Pastora Sala Public Interest Law Centre 200-393 Portage Ave Winnipeg, MB R3B 3H6

13 July 2016

Re: Letter of Support

I am writing to you in the hopes of remedying the lack of government funded support to individuals with severe physical disabilities, who need 24 hour services for care & safety.

The level of support provided should be determined by a person's individual needs, not whether they have an intellectual disability. People with severe Cerebral Palsy do need 24 hour care in order to live an independent life. Cerebral Palsy affects approximately 1 in 33 births a year in Manitoba. A majority of the adult members of the Cerebral Palsy Association of Manitoba are greatly affected by their physical disabilities, and are limited by this ruling.

The transition from childhood to adulthood for persons living with physical disabilities is very stressful and fraught with worry about where supports will come from. As children, extensive care is provided in the school system through physiotherapy, occupational therapy, speech pathologist, a resource teacher, a social worker, psychologist and a full time educational assistant to aid the student with whatever is necessary. Children also benefit from the Children's Rehabilitation Centre, with equipment, bicycles, and consistent monitoring by professionals. All of this support and funding is abruptly stopped on the last school day of the year a person turns 21. Individuals with intellectual disabilities have their future as a post-graduate adult planned carefully by their team, but those supports are not offered to people with severe physical disabilities.

Home life is also greatly affected. Aging parents can no longer safely assist with the necessary physical care required by an adult. This includes (but is not limited to) toileting, dressing, bathing, feeding, positioning in bed, daily physiotherapy, transferring from wheelchair to another location, and the many other tasks that are part of daily living. Adults with disabilities

do not want to live in their childhood home permanently either. They desire, rightfully so, to be an independent adult living in the community.

Cerebral Palsy is life-long neurologically-induced motor impairment. It is permanent and it is a condition, not a disease. Often those affected with CP experience secondary conditions associated with CP, behaviour, sensory, and perception challenges. Individuals with CP whose motor function (mobility, strength, and endurance) is limited or affected are at high risk of having decreased function especially as they age. CP will not go away or get better and the onset of aging for individuals affected by CP will be earlier than in persons in the general population.

Recently the Manitoba Government has begun to implement the Supports Intensity Scale with adults living with intellectual disabilities. This tool is used to determine what level of support a person will require to live as independent a life as possible in the community. I would suggest that it could be used very effectively for people living with severe physical disabilities as well, with very few, if any, modifications.

I appreciate your consideration and support, and look forward to hearing from you in the near future.

Sincerely,

David Kron, Executive Director, CPAM