Submission to the Commission for the Review of Social Assistance in Ontario

Cystic Fibrosis Canada

March 16, 2012
Introduction
Cystic Fibrosis Canada welcomes the opportunity to provide input to the Commission’s Review of Social Assistance in Ontario. To better serve Ontarians with cystic fibrosis (CF), Cystic Fibrosis Canada believes transformation of the social assistance systems is required. In this submission, we will address issues of specific concern to the CF community. As well, in general, we support the comments from ARCH Disability Law Centre.

Cystic Fibrosis
Cystic fibrosis is the most common fatal genetic disease affecting Canadian children and young adults. It is a rare, chronic illness that is present from birth and progresses in severity over time; lung disease remains the primary cause of death and lung transplantation becomes necessary at end-of-life. There is no cure.

Today nearly 60% of all individuals with CF in Canada are adults. With the increasing median age of survival, Canadians with CF face complex health issues associated with aging. In 2010, 28% of CF individuals 35 years of age and older had CF-related diabetes; 31% of female adults and 19% of male adults were classified as underweight; other co-morbidities include osteoporosis, liver disease, pancreatic insufficiency and infertility. As individuals with CF age and their disease progresses, it is increasingly more difficult for many to work full-time and, as a result, they often face significant financial struggles.

Through a provincial network of 13 CF clinics and three outreach clinics, Ontario provides integrated care to over 1,440 individuals with CF, who, along with caregivers, are active partners in managing their disease to ensure optimal health.

Key areas
The following issues raised in the Commission’s discussion papers are the key areas of concern for Ontarians with cystic fibrosis:

a) Training, education supports and addressing employment barriers
b) Inconsistent assessment of disability
c) The Special Diet Allowance
d) Definition of disability and ability
e) Extended health benefits
f) Income security

A. Training, Education Supports and Addressing Employment Barriers
Focussing on employment to eliminate poverty is not realistic in the current job climate. To better assist individuals with cystic fibrosis and help them become actively engaged in the labour force to the maximum of their abilities, it is necessary to provide integrated pre- and post-employment services and supports. These services and supports need to be more comprehensive, available for a longer period of time and tailored to individual needs. Currently, there is limited access to appropriate training for in-demand jobs and inadequate accountability for the effectiveness of the supports that are available.
The attitudinal barriers of employers must be addressed. Employers need to be better trained and educated so they can provide a flexible, adaptive workplace for individuals with episodic illnesses and better manage return-to-work programs. Although the Accessibility for Ontarians with Disabilities Act (AODA) is implementing the Accessibility Standard for Employment over the next five years, there is an urgent need to address the concerns of the CF community in Ontario today.

Going forward, non-profit corporations, such as Cystic Fibrosis Canada, may be able to fill some of the gaps in the current system. Some individuals with CF fear that engaging in employment will put critical, life-saving benefits at risk. Effective employment supports must take into consideration the real risks inherent into moving into a job, such as health limitations, employer resistance to accommodation requirements or simple economic downturn.

Employers may benefit from an Accommodation Fund that could be made available to accommodate for individuals with cystic fibrosis in the workplace. In particular, people with CF may benefit from flexible work hours, the ability to work from home, and the ability to perform therapy and treatments during the day.

Lastly, to improve employment services to individuals with CF, it is necessary that this community is able to access the same services available to other jobseekers. With improvements to provincial-municipal collaboration between Ontario Disability Support Program (ODSP), Employment Ontario (EO) and Ontario Works (OW), more effective employment services and supports could be delivered.

B. Inconsistent Assessment of Disability

The concern with currently used assessment tools is that they are not meeting the needs of individuals with cystic fibrosis and others with episodic illnesses, and they could be used to reduce someone’s benefits if they are deemed employable. The health of persons with CF can change from day-to-day. If assessment tools are used, they must be employed on an on-going basis to benefit people whose course of illness changes continually throughout any given year or period of time. Another concern is the level of training and the qualifications of the individual conducting the assessment in regards to their understanding of the needs and concerns of individuals with CF. Cystic Fibrosis Canada could play a partnership role, helping individuals with CF become effective patient advocates, while providing education and training to the assessor. There are also health and safety issues concerning job assessments by unqualified persons.

Rather than spending money on improving assessment tools, which need constant updating and monitoring, Cystic Fibrosis Canada believes that the money could be better invested in training individuals with cystic fibrosis for job readiness, workplace advocacy, and skills upgrading or training for in-demand jobs. The assessment may be better used to outline what programs and services an individual is provided based on their disability. Cystic Fibrosis Canada’s recommendation, regarding the implementation of work capacity assessments, is to wait until substantial progress has been made on removing barriers to employment for people with disabilities, including the Province’s full implementation of the AODA.

C. Special Diet Allowance

The proposal to roll the Special Diet Allowance (SDA) into a basic standard rate poses a high level of risk to persons with CF, because it means eliminating funding for dietary treatment that is life-saving. Adequate nutrition is directly linked to the quality of life for people with cystic
fibrosis and inadequate support through the SDA will result in more hospitalizations and more sick days which will greatly impact healthcare resources and costs. It is vital that any changes to this program take into consideration the unique needs of individuals with cystic fibrosis. Cystic Fibrosis Canada requests that the CF community be consulted and involved in any proposed changes to the Special Diet Allowance.

D. Definition of Disability and Ability

Cystic Fibrosis Canada has concerns with respect to categorizing disability ‘severity’ and segregating individuals under the benefit structure as it would result in distinguishing between persons with disabilities that can work and those that cannot. Once labelled, it is difficult to move between systems. The current definition of disability in the ODSP is one of its strengths. Regressive changes premised on a perceived inherent “ability” or “inability” to work should not be made. The heart of the ODSP is a comprehensive and flexible definition of disability that supports the episodic nature of certain disabilities. Cystic Fibrosis Canada sees this as a positive to the program as the same person may fall into either category depending on the degree of accommodation available in the workplace or the impact of their disability on their health at any given time.

E. Extended Health Benefits

The ODSP should support part-time work of people with disabilities. For many individuals with cystic fibrosis, part-time work is a long-term or permanent feature of their lives rather than being a short-term transition to employment. People with CF should be able to improve their living standards through retention of part-time employment earnings, especially in the absence of meaningful increases to ODSP rates.

Cystic Fibrosis Canada strongly supports extended healthcare benefits for individuals with cystic fibrosis working in temporary, part-time, or low-wage jobs. Our community has expressed the availability of health benefits as an incentive in seeking social assistance rather than part-time employment which would not cover the costs of their medications and therapies.

F. Income Security

The major employment issue for individuals with cystic fibrosis under the current benefit structure is that it is not possible to work part-time and receive partial benefits. The benefit structure should ensure that work pays; in other words, that there is sufficient financial incentive for a person to take on employment. If the structure were to change to allow for part-time work, more Ontarians with CF would be working, productive, tax-paying citizens, rather than contributing to the growing number of individuals receiving social assistance.

An income supplement as outlined in the discussion paper could help someone with a low income. However, it would have to be indexed to inflation which would require monitoring. Currently, OW and ODSP are not keeping up with inflation. The main issue with the income supplement is that it would reflect the previous years’ earnings. If an individual falls ill at the beginning of the year, they will have to wait an entire year before the income supplement reflects their current situation. This is the biggest challenge for certain illnesses like cystic fibrosis which can be unpredictable.
Closing Comments

Cystic Fibrosis Canada is aware of the challenging fiscal conditions currently facing the Ontario government and the backdrop of economic uncertainty that can affect our goal of improving employment outcomes for people with disabilities and/or chronic illnesses. Cystic Fibrosis Canada investments have helped to cultivate research and clinical care excellence in Canada, contribute to sustaining our economy, generate new commercial opportunities and improve the quality of life for individuals with CF. We will continue to mobilize all partners in advancing the cystic fibrosis agenda, so individuals with CF receive job fairness and readiness, and the services and supports they require for healthy living.

Cystic Fibrosis Canada thanks the Commission for the opportunity to express the concerns and issues of Ontarians with CF in regards to the review of the Province’s social assistance system. We welcome the opportunity to partner with the Ontario government to provide further insight and help transform the social assistance system so it better serves Ontarians with disabilities.

Cystic Fibrosis Canada

Cystic Fibrosis Canada is national health charity with over 50 chapters across the country. Cystic Fibrosis Canada is the coordinating body that mobilizes all partners involved in moving the management of cystic fibrosis forward. Our core responsibilities to improve CF health outcomes include: helping people with CF navigate the health care system in collaboration with the multidisciplinary CF clinic team; developing educational tools and guidelines for healthy living; and funding innovative research projects and clinical studies towards a cure, or effective control, for CF.

Cystic Fibrosis Canada is a global leader in CF research and care, investing more dollars in life-saving cystic fibrosis research and care than any other non-government agency in Canada. In the past two years alone, Cystic Fibrosis Canada invested over $16 million across the country, with nearly $7 million towards research and clinical care at 19 hospitals, universities and research institutes across Ontario.