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CAPSTONE PROJECT

Policy Options for Federal Disability Programs – The Disability Tax Credit (DTC)
Improving Accessibility for Adults with Cystic Fibrosis (CF)

Submitted by:

Harvey Ronald Rabin

Approved by Supervisor:

Jennifer Zwicker

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Capstone Executive Summary

The Disability Tax Credit (DTC) is fundamental to federal Canadian disability programs. Not only by qualifying for a very substantial tax benefit, retroactive over the previous ten years, but also in the sense that the definitions and qualifications of disabling disease are the necessary prerequisites to many of the other federal programs of potential benefit to adults with cystic fibrosis (CF). The problem outlined here is based on the fact that the disabling disease of adults with CF is not reflected in the structure of the disability definitions within the Income Tax Act.

It is the intent of this report to suggest options, beginning with the statement that the status quo is not at all preferred. Alternatively, two policy considerations to amend what is perceived as distinct legislative disadvantages to Canadian adults with cystic fibrosis are:

- redefine disability by using CF-specific disease criteria that are well accepted as physiologic gradations of disabling functional abilities. As part of this intent, also consider how to include other chronic diseases in this redefinition.
- initiate how to act as patient advocates to assist CF patients to present their rationale best for qualifying within the current taxation rule structure.

As with everything else in medicine, a compromise solution may lead to rewriting the clinical definitions into the next iteration of disability legislation and the new proposed Canadians with Disabilities Act.

Policy Options for Federal Disability Programs – The Disability Tax Credit (DTC)
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Introduction

Approximately one in seven Canadians now has a disability. Three-quarters of Canadians without disabilities know someone with a disability. Given that the incidence of disability increases with age, more Canadians will be soon affected by disability. In a 2009 Government of Canada report on *Advancing the Inclusion of People with Disabilities,* the indicators of change are disability supports and services, education and training, employment and income, and health and well-being.[1] Canada is a world leader in its employment equity legislation, expenditure programs, targeted tax measures, and community services all in support of people with disabilities and their families.

Canadians, communities, and workplaces benefit when everyone can participate equally in everyday life. There has been much progress in making our Canadian society more inclusive by improving accessibility and removing barriers in areas of federal legislation.[2] But we can do better.[3]

The etiologies of disabilities are many, including developmental (genetic or congenital), traumatic, or due to chronic illnesses or the aging process. Many Canadians with chronic disabling disease do not benefit from public or private disability insurance programs because availability is a workplace benefit. Even if employed, typically their earnings are modest, their employers do not provide disability insurance, and they cannot afford to insure themselves privately. Their income falls below the threshold to owe income tax, and so the DTC is of no advantage.

[1] Human Resources and Skills Develpment Canada, "2009 Federal Disability Report: Advancing the Inclusion of People with Disabilities," http://www.esdc.gc.ca/eng/disability/arc/federal_report2009/fdr_2009.pdf.
[2] Richard H. Carmona et al., "The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities: Historical Review, Rationale, and Implications 5 Years after Publication," *Disability and Health Journal* 3, no. 4 (2010).
[3] Employment and Social Development Canada, "Accessibility Legislation - What Does an Accessible Canada Mean to You? - Discussion Guide," (2016).

The Government of Canada is developing new planned accessibility legislation to promote equality of opportunity and increase the inclusion and participation of Canadians who have disabilities or functional limitations.[4]

Many disabled Canadians continue to face barriers that affect their ability to participate in daily activities that most people take for granted. These could include:[5]

- physical and architectural barriers that impede the ability to move freely in the built environment, use public transportation, access information or use technology;
- attitudes, beliefs, and misconceptions that some people may have about people with disabilities and what they can and cannot do; and
- outdated policies and practices that do not take into account the varying abilities and disabilities that people may have.

The Government of Canada has a steadfast commitment to enriching the lives of Canadians with disabilities and their families. The need is to develop an understanding of disability; provide information on the nature and severity of disabilities of varying definitions; and develop tools, policies, and programs to measure progress. In addition, there is a need to form an auditing mechanism to determine whether program expenditures are benefitting the Canadians they are intended to assist.[6]

In Canada, in 2012, it is estimated that among approximately 3.6 million people, 13.7%, report having a disability with more women than men in every age group reporting a disability. The prevalence of disability increases steadily with age: 2.3 million working-age Canadians (15 to 64), or 10.1%, reported having a disability in 2012, compared to 33.2% of Canadian seniors, those aged 65 or older.[7] Within the working-age population, those reporting a disability was 4.4% for people aged 15 to 24, 6.5% for those 25 to 44 and 16.1% for those 45 to 64. This proportion reaches 26.3% for those aged 65 to 74 and 42.5% among those 75 and older.

Equality for disabled Canadians implies both shared employment opportunities and increased access to federal, provincial and private work-related disability benefits. The focus of

[4] Annalise Klingbeil, "National Disabilities Act Plan Praised by Activists," *Calgary Herald*, March 25, 2016.
[5] Government of Canada, "Consulting with Canadians on Federal Disability Legislation," http://www.esdc.gc.ca/en/consultations/disability/legislation/index.page.
[6] J.R. Graham, K.J. Swift, and R. Delaney, *Canadian Social Policy: An Introduction* (Toronto, Ontario: Pearson Canada Inc., 2012).
[7] Statistics Canada, "The 2012 Canadian Survey on Disability (Csd) and the 2006 Participation and Activity Limitation Survey (Pals)," (2016), http://www23.statcan.gc.ca/imdb-bmdi/document/3251_D6_T9_V1-eng.pdf.

this policy discussion is about inclusive accessibility for federal disability benefits that are not specifically available to adults who suffer severe, prolonged and irreversible disabilities of chronic illness. Adults with cystic fibrosis (CF) meet this need.

What is required is a renewal of the legislation specific to CF disability that would be more responsive to and inclusive of qualified individuals with this specific chronic disease. Necessary is either a redefinition to include more physiologic functional definitions of severe, permanent and progressively disabling disease, or a more open and tolerant policy that would fairly qualify those who suffer disabling effects of CF.

Background

The World Health Organization's (WHO) definition states that "Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives."[8]

The International Classification of Functioning, Disability and Health (ICF) emphasizes functional status over diagnosis.[9] The ICF calls for the elimination of distinctions between health conditions that are 'mental' or 'physical.' While for some people a disability can be a lifelong issue which starts at birth, for others a disability may arise after a certain incident or time in one's life. In either case, though, you should know that a disability is a serious matter, which depending on the severity of the condition, may greatly hamper normal functioning.

Federal Disability Tax Credit (DTC)

The Canada Revenue Agency (CRA) offers Canadians with disabilities multiple options, both tax credits, and tax deductions, intended to alleviate some of the tax burdens given that they suffer prolonged and severe disease.[10] Included are the Disability Tax Credit, the Registered

[8] World Health Organization, "Towards a Common Language for Functioning, Disability and Health - Icf," World Health Organization, Geneva, http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1.
[9] Ibid.
[10] "Tax Credits and Deductions for Persons with Disabilities," Canada Revenue Agency, accessed November 3, 2015, http://www.cra-arc.gc.ca/disability/.

Disability Savings Plan, the Disability Supports Deduction, the Child Disability Benefit, and the Medical Expenses Tax Credit (Table 1). "The Disability Tax Credit provides both federal and provincial/territorial income tax relief to help cushion the burden of non-discretionary disability-related expenses."[11]

Table 1: Canada Revenue Options for Disability Tax Credits and Deductions

Disability Tax Credit (DTC)[12]	The *Disability Tax Credit* (DTC) is a non-refundable tax benefit that helps an individual living with a severe and prolonged impairment in physical or mental functions receive credit on their annual personal taxes. Rather than assuming a traditional welfare role, the goal is to accommodate people with disabilities better. Qualifying for the DTC is a prerequisite for all but the Family Caregiver Tax Credit. The DTC benefits also require support from a medical practitioner to qualify. Tax credits are classified as 'refundable' or 'non-refundable', the latter applying to the DTC.[13] [14] Non-refundable tax credits reduce your taxes owing. If a tax credit is identified as non-refundable, money is not refunded if more tax credits exist than taxes owing.
Medical Expense Tax Credit (METC).[15]	The federal government issues credits for eligible medical expenses.
Canada Pension Plan Disability Benefit (CPP-D)[16]	The Canada Pension Plan disability benefit (CPP-D) is a taxable monthly payment that is available to people under the age of 65 who have contributed to CPP and who are not able to work regularly at any job because of a disability. The CPP disability benefit is not designed to pay for such things as medication and assistive devices.

[11] Michael Mendelson et al., "A Basic Income Plan for Canadians with Severe Disabilities," (2010), accessed November 3, 2015,http://www.caledoninst.org/Publications/PDF/906ENG.pdf.
[12] http://www.cra-arc.gc.ca/tx/ndvdls/sgmnts/dsblts/dtc/glssry-eng.html#prlngd
[13] Michael Mendelson, "Options for a Refundable Disability Tax Credit for 'Working Age' Persons," Caledon Institute of Social Policy, http://www.caledoninst.org/Publications/Detail/?ID=1079.
[14] Wayne Simpson and Harvey Stevens, "The Disability Tax Credit: Why It Fails and How to Fix It," The School of Public Policy, http://www.policyschool.ca/wp-content/uploads/2016/07/disability-tax-credits-simpson-stevens.pdf.
[15] http://www.cra-arc.gc.ca/tx/ndvdls/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330/llwbl-eng.html
[16] http://www.servicecanada.gc.ca/eng/services/pensions/cpp/disability/benefit/index.shtml

Registered Disability Savings Plan (RDSP)[17]	The *Registered Disability Savings Plan* (RDSP) is a plan to help Canadians with disabilities, under the age of 60, and their families develop a long-term savings plan for the future. This savings plan helps parents and others save for the long-term financial security of a disabled person. The Government of Canada assists by paying a matching Canada Disability Savings Grant. Individuals who open an RDSP may also be eligible to receive a Canada Disability Savings Bond.
Family Caregiver Tax Credit (FCA)[18]	Launched in 2013, the *Family Caregiver Tax Credit* (FCA) is a non-refundable credit that provides tax relief to those who care for a person who is dependent on the individual because of impairment in mental or physical functions. The family caregiver amount is the only one not tied to the disability tax credit.

The fragmentation of policies on disabilities seems obvious. The House of Commons Standing Committee on Human Rights and the Status of Disabled Persons, in their report entitled, *A Consensus of Action: The Economic Integration of Disabled Persons*,[19] noted the inconsistent, ambiguous, and contradictory policies, and issues of concern to persons with chronic disabling diseases. There is an argument that disability, "*is a social construction, often more reflective of the fears and feelings of others than of the experiences of people with disabilities*."[20]

Getting it Right for Canadians was adopted, in March 2002, by the Standing Committee on Human Resources Development and the Status of Persons with Disabilities[21] to examine the disability tax credit. Also at this time the Technical Advisory Committee on Tax Measures for

[17] http://www.esdc.gc.ca/eng/disability/savings/index.shtml
[18] http://www.cra-arc.gc.ca/tx/ndvdls/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/315/menu-eng.html
[19] "A Consensus for Action: The Economic Integration of Disabled Persons, Second Report," ed. Standing Committee on Human Rights and the Status of Disabled Persons House of Commons (2nd Session, 34th Parliament, June 1990).
[20] Graham, Swift, and Delaney.
[21] Judi Longfield and Carolyn Bennett, "Getting It Right for Canadians: The Disability Tax Credit - Standing Committee on Human Resources, Development and the Status of Persons with Disabilities," Parliament of Canada, http://www.parl.gc.ca/HousePublications/Publication.aspx?DocId=1032069.

Persons with Disabilities published the *Tax Fairness for Persons with Disabilities* with its goal to promote a more equitable tax system.[22]

The Canada Revenue Agency offers a substantial tax benefit to all who suffer prolonged and severe disabling disease. The DTC offers a federal tax credit of considerable value (Table 2) that amounts to a significant tax saving.[23] Furthermore, the DTC can apply retroactively to cover up to a maximum of 10 prior years provided that the duration of the disability remains eligible for the tax credit.

TABLE 2: Maximum disability tax credit amounts

Year	Maximum Disability Amount
2015	$7,899
2014	$7,766
2013	$7,697
2012	$7,546
2011	$7,341
2010	$7,239
2009	$7,196
2008	$7,021
2007	$6,890
2006	$6,741
2005	$6,596

From the Caledon Institute of Social Policy, Mendelson estimates that approximately 755,000 working-age Canadian residents would qualify for the DTC but do not benefit as they do not have sufficient taxable income.[24] Projecting to 2014, Simpson and Stevens have updated estimates on the numbers of Canadian adults qualified for the disability tax credit for themselves to be 499,302.[25] "*Another 180,883 adults qualified for the disability tax credit for dependents, alluding to a combined total of 680,185 qualifying adults…The disability tax credit for oneself had no effect on 301,458 (60 per cent) of the 499,302 eligible for the credit because they either had no taxable income or their basic federal tax payable was less than the value of their*

[22] Judi Longfield, "Tax Fairness for Persons with Disabilities: Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities," http://www.parl.gc.ca/content/hoc/Committee/372/HUMA/Reports/RP1032189/HUMArp1/HUMArp1-e.pdf.
[23] Ibid.
[24] Michael Mendelson, "Options for a Refundable Disability Tax Crdit for 'Working Age' Persons," (2015), accessed November 3, 2015,http://www.caledoninst.org/Publications/Detail/?ID=1079.
[25] Simpson and Stevens.

combined non-refundable tax credits. An additional 5,895 filers of those eligible (one per cent) paid no federal taxes, thus limiting the value of the disability tax credit to only $327. For the remaining 191,949 of those eligible for a disability tax credit (38 per cent), it resulted in a reduction of their federal taxes of $1,163, just slightly lower than the maximum amount of $1,165. As a result, the average value of the disability tax credit across all eligible claimants was only $553."

This can be interpreted as indicating that these residents are unemployable, and thereby not earning, not paying income taxes, and not at all able to take advantage of the significant taxation savings. In such situations the DTC applies only for those with disabilities so advanced that gainful employment is impossible. As the qualification requirements are not universally approved for all Canadians, except those with severe and prolonged disabilities, then those still employed/employable will remain ineligible. Such is the case for adults with cystic fibrosis. As recommended by Simpson and Stevens, making the DTC refundable would help make the DTC accessible to those who qualify for the credit but lack sufficient income to benefit.

A 2014 federal consultation process gathered ideas for improving the tax credit. They questioned if the application process was cumbersome, or if the qualifications were too restrictive.[26] They concluded there was a "need for tax simplification."[27] The DTC as outlined in the Income Tax Act (ITA)[28] specifies the definitions of disabling disease – in relevant sections 152 (1.01) and 118.3 (1), (1.1). Sections 118.3 (2) and (3) define the similar tax credit regulations for immediate family caregivers. The clarification of the policy is best outlined in the Disability Tax Credit Certificate T2201[29] in the accompanying patient information sheet,[30] including its latest revision.[31]

[26] Ibid.
[27] C. Scott Clark and Len Farber, "Issue in Focus: The Need for Tax Simplification – a Challenge and an Opportunity " (2011), accessed November 3, 2011 http://www.cga-canada.org/en-ca/researchreports/ca_rep_2011-08_tax_simplification.pdf.
[28] "Income Tax Act, Rsc 1985, C 1 (5th Supp)," (CanLII, 2015), accessed November 11, 2015, http://canlii.ca/t/52hdp.
[29] "Disability Tax Credit Certificate - T2201-1," ed. Canada Revenue Agency (2015), accessed November 7, 2015, http://www.cra-arc.gc.ca/E/pub/tg/t2201-1.
[30] "Disability Tax Credit Certificate - T2201-15e Information Sheet," ed. Canada Revenue Agency (2015), accessed November 7, 2015, http://www.cra-arc.gc.ca/E/pbg/tf/t2201/t2201-15e.pdf.
[31] Canada Revenue Agency, "Definitions for the Disability Tax Credit," (Government of Canada, 2016).

What is CF? What is it about CF that pertains specifically to the DTC?

Cystic fibrosis is an autosomal recessive inherited metabolic disease characterized by tenacious glandular secretions causing mucous plugging, glandular and ductal obstruction and progressive loss of organ function. It affects both lungs and pancreas primarily. Cystic fibrosis used to be thought of as a children's disease. Medical management promotes significantly improved survival outcomes of what historically was a fatal chronic disease of children and young adults. Canadian CF patients attended over 15,500 CF-specific outpatient clinic visits in 2014; cumulatively they spent almost 25,000 days in the hospital. That adds up to 68.5 years![32] Thanks to significant progress in treatment and care, the majority of children with CF will easily reach adulthood. Nevertheless, of the 54 Canadian patients who died in 2014 of CF-related complications, half were under 32.4 years of age (Figure 1). The most recent data for 2014 shows the estimated median survival age to be 51.8 years of age (Figure 2). The interpretation is that a child with CF born in Canada in 2014 will have a 50% chance of living beyond 51.8 years. The age of individuals living with cystic fibrosis today ranges from birth to almost 80 years old. The median age of all individuals reported on in 2014 was 21.9 years, almost nine years higher than it was in 1989! 59.7% of individuals are over age 18 years of age. It is now a ten-year fact that the majority with CF are now adults.

These CF Canada Registry facts confirm that the success of CF management and the protraction of longevity will lead to proportionally greater numbers of disabled patients attending CF clinics in Canada. The longer survival means significantly more disabled adults are succeeding into older age groups. Failure with disability benefit policies is measurable. The goal is to determine if the majority of disabled patients are disadvantaged in respect to the criteria of selected benefit plans.

Policies such as the federal disability tax credit do not always present favorably for the adult with cystic fibrosis and advancing lung disease. The two patient priorities for longevity with CF are to stabilize weight and prevent worsening of pulmonary function. The former depends on the success of the latter. The main concern in having CF is the complicating chronic suppurative lung infections resulting in permanent, progressive and severe respiratory failure. Disability in

[32] Cystic Fibrosis Canada, 2016, www.cysticfibrosis.ca.

CF is superficially invisible as compared to a physical and more visible infirmity such as paraplegia or amputation.

As persons with CF live longer, their advancing aging brings higher rates of infirmity. The longer they survive, the more likely they will suffer progressively worsening disabilities. This longer lifespan comes with complicating medical problems that prevent the ability to perform activities of daily living. These often result in the requirement for disability benefits (CPP), the disability tax credit (DTC), and an all too often need for provincial social benefits such as assured income for the severely handicapped (AISH here in Alberta), and short and long-term disability leaves from work or school. Even the Canada Pension Plan (CPP-D), to qualify for disability benefits, requires the DTC application to be successful.

The status quo is not acceptable. Even though the current policies offer qualifying alternatives and thereby some CF patients can still qualify for income tax credit, the fact is that a majority of others with CF-related disabilities remain ineligible for the tax credit.

Inclusiveness of the DTC for Disabling Chronic, Progressive and Severe Diseases, Such as CF, Does Not Currently Exist

Cystic fibrosis is a chronic disease that fulfills the major four DTC qualifying criteria. But the reality is that adults with CF only qualify once the advanced stages of the disease thwart any real need for the DTC. Canadians with chronic disease-causing hidden disabilities might require life-sustaining therapy, but possibly only at the advanced point when their illness prevents continuous gainful employment. They are no longer employed nor employable. They no longer pay income tax and are thereby disadvantaged from any taxation saving of the DTC. For these resons a refundable disability tax credit might be relevant.[33]

[33] Simpson and Stevens.

Figure 1: Age at Death, CF Canada, CF Canada, 2010-2014[34]

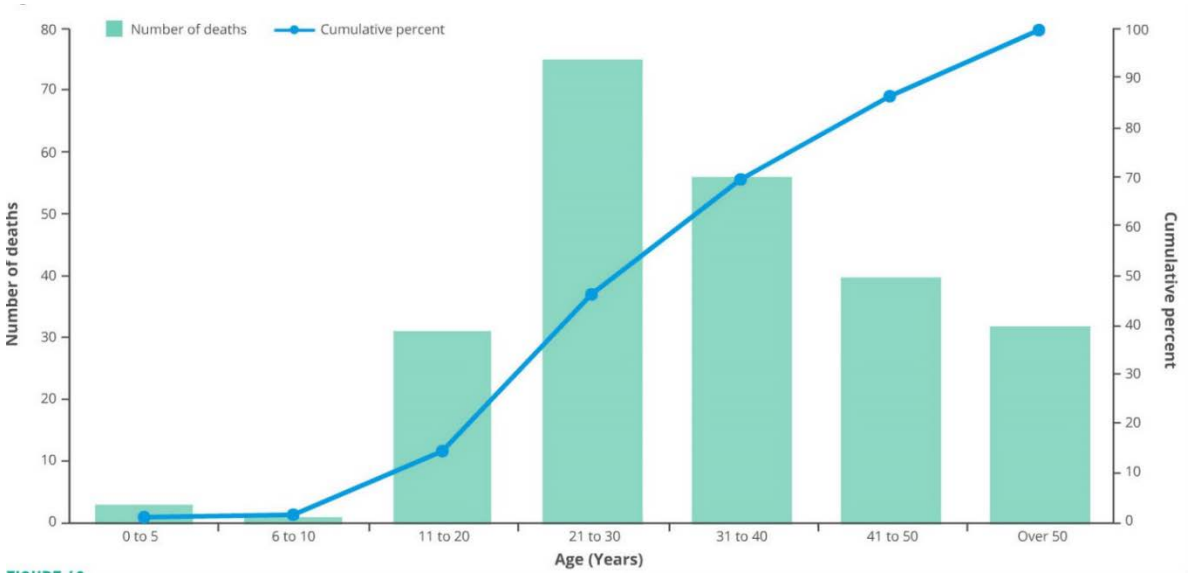
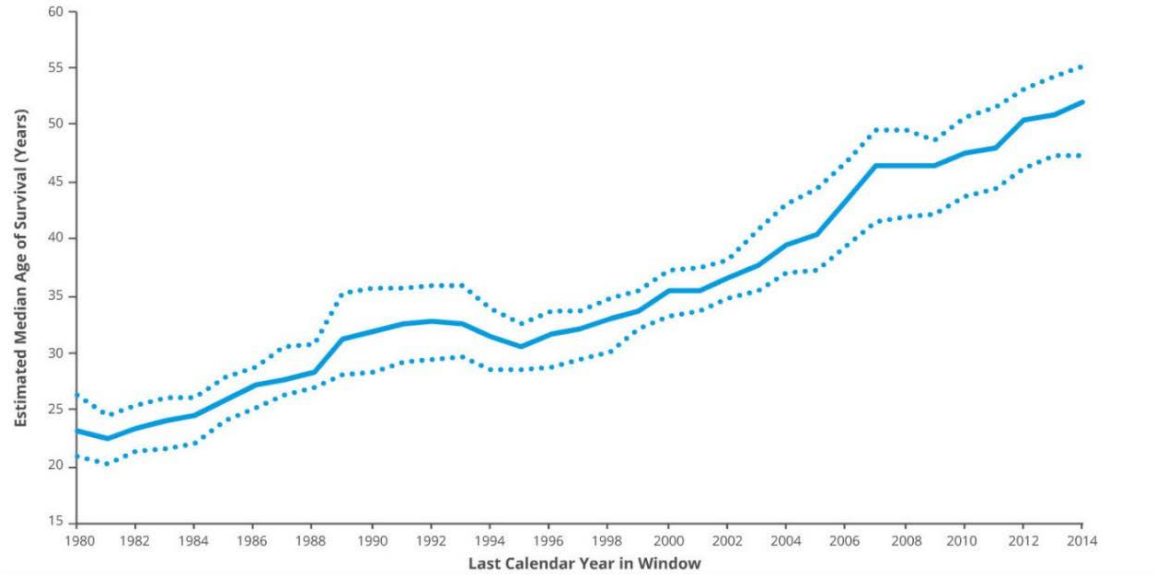


Figure 2: Median Age of Survival for a Moving 5-Year Window (with 95% confidence intervals) CF Canada, 1980-2014[35]



[34] Cystic Fibrosis Canada, "The Canadian Cystic Fibrosis Registry - 2014 Annual Report," https://cysticfibrosis.uberflip.com/i/705240-cystic-fibrosis-canada-registry. (Figure 43)
[35] Ibid. (Figure 41)

There is no argument about the eligibility of Canadians who are visually impaired, who require assisted devices to speak or communicate, who lip read or must use sign language (despite the use of a hearing aid), who are confined to a wheelchair outside the home, who experience fatigue or imbalance such that it takes an inordinate amount of time to mobilize from one location to another, who need device assistance in respect to toilet functions, who either cannot prepare meals or feed themselves or who need tube feedings, who cannot dress themselves due to pain or stiffness, or who have significant mental impairment. There is much more to disability than simply qualifying because of a prolonged time to accomplish these activities of daily living.

To qualify, adults with cystic fibrosis, especially those who are gainfully employed and yet quite disabled enough to benefit from a taxation credit, will not be proven eligible by current application standards set out by the Canada Revenue Agency. Regarding the DTC and its eligibility rules, maintaining the status quo is not satisfactory.

The qualifying definitions for all individual DTC certificate applicants, especially those with a wide range of chronic disabling diseases such as CF, are so strict that most will usually fail to meet the formal government acceptable criteria for the DTC. These are the definitions of the four major criteria:

- one or more impairments of **basic activities of daily living**[36] (speaking, hearing, walking, eliminating, feeding, dressing, and mental functions, all deemed necessary for everyday life);
- that it takes an **inordinate amount of time** to compensate for the impaired daily activity (three times the normal time needed to complete the activity by a person who does not have the impairment);
- that the effects of the impairment(s) be **markedly restrictive all or substantially all of the time** (at least 90% of the time), even with therapy, appropriate devices, and medication; and
- that the impairment be **prolonged** if it has lasted, or is expected to last, for a **continuous period of at least 12 consecutive months** (with some allowance for variations in this requirement).

[36] Highlighting in bold as per the Disability Tax Credit Certificate

Clarification of infirmity also includes these additional essentials:

- the infirmity must be **severe, progressive and irreversible**;
- the infirmity must meet the two criteria for **life-sustaining therapy** (see below);
- it required, infirmity might also meet the definition of **cumulative effect of significant restrictions** that exist all or substantially all of the time (only if any of the markedly restricted activities do not seem to apply to any one of the basic activities of daily living); and
- the effects of the impairment(s) cause restriction **all or substantially all of the time**.

Details of the medical qualifications for the DTC are part of the medical practitioner's attestation within Part B of the Disability Tax Credit Certificate – T2201-1.[37] It is mandatory that the certifying medical practitioner describes the effects of the impairment on the applicant's ability to perform each of the basic activities of daily living indicated as markedly or significantly restricted on Part B of the Certification for the DTC.[38] A Canada Revenue Agency self-assessment questionnaire is available to patients and physicians who so often get confused by the jargon of these definitions and qualifications.[39]

Without exception, such overt disabilities would reduce the applicants' eligibility for equal gainful employment compared to able individuals. If disabled individuals remain employed and submit to scheduled income tax deductions from their earnings, then they must be perceived as eligible for tax credit benefits as per the eligibility rules as defined in the Income Tax Act mentioned above.

A 2014 federal consultation process was asked to gather ideas for improving the tax credit. They question if the application process is cumbersome, or if the qualifications are too restrictive.[40] There is a "need for tax simplification."[41] The DTC as outlined in the Income Tax Act (ITA)[42] specifies the definitions of disabling disease – in relevant sections 152 (1.01) and

[37] "Disability Tax Credit Certificate - T2201-1."
[38] "Disability Tax Credit Certificate - T2201-15e Information Sheet," ed. Canada Revenue Agency (2015).
[39] Canada Revenue Agency, "Tax Measures for Persons with Disabilities: Disability Related Information, 2015," (2015).
[40] Ibid.
[41] C. Scott Clark and Len Farber, "Issue in Focus: The Need for Tax Simplification – a Challenge and an Opportunity " (2011), accessed November 3, 2011 http://www.cga-canada.org/en-ca/researchreports/ca_rep_2011-08_tax_simplification.pdf.
[42] "Income Tax Act, Rsc 1985, C 1 (5th Supp)," (CanLII, 2015), accessed November 11, 2015, http://canlii.ca/t/52hdp.

118.3 (1), (1.1). Sections 118.3 (2) and (3) define the similar tax credit regulations for immediate family caregivers. The clarification of the policy is best outlined in the Disability Tax Credit Certificate T2201[43] in the accompanying patient information sheet,[44] including its latest revision.[45]

Given that the DTC lacks clarity of definitions there is confusion as to whether a disabled person with CF is or is not eligible. A 1998 appeal to the Tax Court of Canada, Scott L. Froese and Her Majesty the Queen, was allowed. [46] The Honorable Justice D.G.H. Bowman states the legislative intent of the DTC and provides clarification of the tax rulings:

> *The legislative intent appears to be to provide a modest relief to persons who fall within a relatively restricted category of markedly physically or mentally impaired persons. The intent is neither to give the credit to everyone who suffers from a disability nor to erect a hurdle that is impossible for virtually every disabled person to surmount. It obviously recognizes that disabled persons need such tax relief and it is intended to be of benefit to such persons. The learned Judge went on to add, at p. 2529, and I agree with him: If the object of Parliament, which is to give to disabled persons a measure of relief that will to some degree alleviate the increased difficulties under which their impairment forces them to live, is to be achieved the provisions must be given a humane and compassionate construction.* [47]

The DTC Fails to Work for Adults with Cystic Fibrosis

Many chronic disease-related disabilities that are prolonged, severe, and progressive should have the equal advantage to the DTC. Cystic fibrosis is such a disease with "hidden" disabling manifestations that are not in any way related to speaking, hearing, walking, eliminating, feeding, or dressing. Hidden disabilities do not necessarily limit activities of daily living. [48] The

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[43] "Disability Tax Credit Certificate - T2201-1," ed. Canada Revenue Agency (2015), accessed November 7, 2015, http://www.cra-arc.gc.ca/E/pub/tg/t2201-1.

[44] "Disability Tax Credit Certificate - T2201-15e Information Sheet," ed. Canada Revenue Agency (2015), accessed November 7, 2015, http://www.cra-arc.gc.ca/E/pbg/tf/t2201/t2201-15e.pdf.

[45] Canada Revenue Agency, "Definitions for the Disability Tax Credit," Government of Canada, http://www.cra-arc.gc.ca/tx/ndvdls/sgmnts/dsblts/dtc/glssry-eng.html#prlngd.

[46] "Disability Tax Credit Case Studies ", *Brematson & Associates, CPP and Disability Tax Credit Advocates* (2015), accessed November 3, 2015,http://www.brematson.ca/case_studies.

[47] "Froese V. The Queen, 1998 Canlii 225 (Tcc)," (CanLII, 1998), accessed November 11, 2015, http://www.canlii.org/en/ca/tcc/doc/1998/1998canlii225/1998canlii225.html?autocompleteStr=froese%2097&autocompletePos=1.

[48] "Disability Tax Credit Certificate - T2201-15e Information Sheet."

Income Tax Act was amended in 1994, attempting to resolve this inequity, by defining "life-sustaining therapy" as a qualifying definition.

There are two criteria for life-sustaining therapy, and applicants must qualify for both. First, therapy for the prolonged and severe disability is necessary to support a vital function: inhalational therapies to support breathing, chest physiotherapy for cough expectoration, chronic oxygen therapy on a continuous use basis, continuous positive airway pressure (CPAP) therapy for obstructive sleep apnea, glucose monitoring for diabetic control, or tube feeding for supplemental caloric intake in order to maintain weight control. One-quarter of persons with disabilities is classified as having a very severe disability.[49] And from the same Statistics Canada report, more than eight out of ten persons with disabilities use aids and assistive devices.

Second, therapy is necessary for a minimum of three times per week for a weekly time duration of 14 hours. It is this requirement that limits eligibility for CF adults. Fourteen hours per week is excessive in the opinion of many medical practitioners who need to signify their confirmation by signing the T2201 application form on behalf of their CF patients. This second requirement results in the qualifying level of disability, namely the requirement for a life-sustaining therapy, becoming a contradiction to the DTC. When CF adults reach the point of requiring life-sustaining therapy they are most likely so severely disabled that gainful employment is impossible, and therefore the DTC benefit of paying income tax is a non-issue. As such, those who should normally benefit from a Disability Tax Credit, most often fail to apply due to the restricted issues around the 14 hours per week qualification.

The issues get complicated because in reality adults with CF might routinely spend 14 hours per week, but a significant component of this qualifying time requirement is for therapies that are ineligible. In the case of chest physiotherapy for an adult with cystic fibrosis (CF), investing two hours per day for what is a qualified life-sustaining therapy is more than is medically necessary. Most cannot claim 14 hours per week. If that same CF patient commits additional time to inhalational antibiotic therapies or a prescribed exercise program, these of themselves could expend the majority of the two-hour time commitment. However, they are told that these are not allowable as life-sustaining therapies.

[49] "Disability in Canada: Initial Findings from the Canadian Survey on Disability," http://www.statcan.gc.ca/pub/89-654-x/89-654-x2013002-eng.htm.

For CF patients and their clinic physicians, it is not understood why the DTC has placed time limitations on life-sustaining therapy. It seems unreasonable to disallow time spent on activities related to prescribed dietary or exercise programs, travel time to receive therapy, recuperation after therapy, attending medical appointments (which can often be frequent and time-consuming), and shopping for prescribed medications. These could amount to more than 14 hours per week. Therapies that require daily dosage adjustment that is acceptable to this second part of the life-sustaining requirements are not perceived the same as the home administration of many unique therapies that are prescribed daily at a standard dosage without daily adjustments necessary. CF patients, for example, require chronic inhalational therapies, sometimes more than one, given sequentially through a specific respiratory delivery device and usually at a minimum of twice daily, but at a standard dose that does not require any calculation. The time required can easily exceed 2 hours per day without meeting the DTC definitions of disability seemingly to acknowledge that their disability fails approval for the DTC.

CF adults must be compliant to routine therapies for what are termed pulmonary infection exacerbations. And whether the therapy requires inpatient or outpatient intravenous antibiotics, the requirement is that they remove themselves from the workplace until sufficient recovery is established. Being chronically ill has inconveniences and disadvantages to maintaining employment – one more reason why CF adults deserve to succeed to get the DTC. Furthermore, there is not an acknowledgement that exacerbations require frequent outpatient clinic visits that routinely can fulfill a half day of effort and inconvenience, and prolonged periods of convalescence that equally inconveniences the patient from returning to work and resuming gainful income. These are perceived by CF medical and healthcare professionals as the main reason not to apply for the DTC as success with the whole process is not guaranteed.

Life-sustaining therapy may be the cause of the hundreds of thousands of Canadians failing to consider qualifying for the DTC.

Completing the DTC medical certification is difficult

Medical practitioners who are mandated with the responsibility to qualify the adult with CF for the DTC uniformly complain that the DTC Tax Credit Certification (T2201-1) are uninterpretable and create confusion such that the medical doctor most often defers that application until the ‘hidden’ disability is so severe as to seem more easily be justifiable.

Details of the medical qualifications for the DTC are part of the medical practitioner's attestation within Part B of the Disability Tax Credit Certificate.[50] The necessity of signing the Medical Certificate by a licensed medical practitioner is another barrier caused by the lack of clarity on the application form itself. The Tax Court of Canada speaks to the inflexibility of the qualifications as prescribed in Part B in the same appeal case to the Tax Court of Canada (as above).[51] Justice Bowman criticizes the rigidity of the medical certificate as "*unacceptable use of technicalities to deny worthy claims . . . I am not, however, prepared to deny this obviously meritorious claim because of a misplaced tick mark*".

The inflexibility of section 118.4 confirms, in the minds of the Court, that severe and permanently disabled persons who do not meet the strict criteria of the Act are therefore ineligible for the DTC.[52] *Mr. Beardwood's objection to the questions had to do with their substance, not his physicians' responses to them. He stated with some force that, in his view, such "ridiculous" questions were not useful in assessing a taxpayer's entitlement to claim a Disability Tax Credit. Mr. Beardwood is not the first and is unlikely to be the last to express frustration with the operation of the Disability Tax Credit provisions in the Act.*

"*There is the need for the tax system to deal in a humane and compassionate manner with Canadians with disabilities by improving the policies and the administration of the income tax system generally -- and the DTC in particular*."[53]

Policy options for CF eligibility criteria: A Change in Eligibility Criteria Could Improve Accessibility?

Three policy considerations to amend what is perceived as distinct legislative disadvantages to Canadian adults with cystic fibrosis are:

1. simply maintain the status quo,
2. consider redefining disability by using CF-specific disease criteria that are well accepted as physiologic gradations of disabling functional abilities; and

[50] "Disability Tax Credit Certificate - T2201-1."
[51] "Froese V. The Queen, 1998 Canlii 225 (Tcc)," CanLII, http://www.canlii.org/en/ca/tcc/doc/1998/1998canlii225/1998canlii225.html?autocompleteStr=froese%2097&autocompletePos=1.
[52] "Beardwood V. The Queen, 2003 Tcc 833 (Canlii)," (CanLII, 2003).
[53] "House of Commons Committees - Huma (37-2) - Tax Fairness for Persons with Disabilities ".

3. act as patient advocates to assist CF patients on how best to present a rationale for qualifying within the current taxation rule structure.

Option 1: Redefining the Disability Tax Credit Certificate

Redefining the DTC is likely to fail. Even though the T2201-1[54] DTC Tax Certificate and especially the guide for defining eligibilities[55] have been recently revised,[56] the required life-sustaining section that documents the support for vital functioning are not necessarily relevant to the inexperienced physician advocating for the DTC on behalf of his CF patient. As described above, the status quo option will continue to result in underutilization of the DTC, particularly for those with CF most in need.

Option 2: Redefining disability in CF based on a physiological definition of pulmonary function

There is a widely accepted clinical definition of progressive disability in CF based on a physiological definition of reduced pulmonary function. It applies to anyone with a chronic lung disease. The forced expiratory volume in one second (FEV_1) is the volume exhaled during the first second of a forced expiratory maneuver started from the level of total lung capacity. It is usually expressed as a percentage of what is referred to as normal predicted, a calculated value from an algorithm that includes the weight, weight for height (BMI), age, and gender of the person being evaluated. There are two direct correlates to pulmonary function that best reflect advancing disease and severe and irreversible disability – the first is the correlation of cause of death with end-stage lung disease (Figure 3)[57], and the second, the correlation of increased 2-year survival rates in patients with an FEV_1 of less than 40% of predicted normal (Figure 4). Neither reflects normal activities of daily living. The clinical interpretation is a grading scale of severity in CF, and as well other chronic disabling pulmonary diseases are repeatedly stated in all guidelines to CF as a disabling chronic disorder (See Table 3).

[54] "Disability Tax Credit Certificate - T2201-1," ed. Canada Revenue Agency (2015).
[55] "Disability Tax Credit Certificate - T2201-15e Information Sheet."
[56] Canada Revenue Agency, "Definitions for the Disability Tax Credit."
[57] Cystic Fibrosis Foundation Patient Registry, "Annual Data Report 2014," https://www.cff.org/2014-Annual-Data-Report.pdf.

Table 3: FEV_1 Percent Predicted and Disease Severity Classification in CF[58]

Classification	Range of FEV_1
Normal	≥ 90%
Mild	70 – 89%
Moderate	40 – 69%
Severe	< 40%

There is a justification of the relationship of deteriorating lung function and the increased risk of mortality. If there was one physiologic measurement of severity in CF, it must be the FEV_1 of less than 40% of predicted normal. Should the FEV_1 be the allowable criterion for DTC qualification?

An FEV_1 of less than 40% predicted normal is the best clinical predictor of the severe and advancing stages of the chronic lung disease complications of CF and is well-accepted based on numerous evaluative studies. At the stage of 40%, or lower, of predicted normal pulmonary function it is recognized that the disease is severe, progressive, and irreversible. The terminal stages of CF correlate with advanced pulmonary disease and complications of lung transplantation, accounting for approximately 83% of deaths (Figure 3). Canadian CF data from 1992 shows the direct correlation of severe reduction in FEV_1 to progressively increased one- and two-year mortality rates (Figure 4).

In Canada, we do not have a criterion based on the frequency of pulmonary infection exacerbations, nor on the relative time of relapse infections. These two clinical criteria are however applied as primary treatment objectives for random controlled CF clinical trials in North America and Europe. Infection exacerbations are very relevant to the lives of adults with CF and yet not perceived to be criteria of disabling chronic disease.

By accepting advanced stage lung function is an excellent surrogate to claim a CF patient as disabled, possibly more adults with CF would be eligible for the DTC. The epidemiologic evidence would suggest that approximately 20% of Canadian CF adults over age 18 years with

[58] Cystic Fibrosis Canada, "The Canadian Cystic Fibrosis Registry - 2014 Annual Report".

an FEV_1 of less than 40% of predicted normal (Figure 5) would qualify as having severe CF lung disease and thereby should benefit from the DTC.[59]

Figure 3: Primary Causes of Death, 2014 (CF Foundation, US Data)[60]

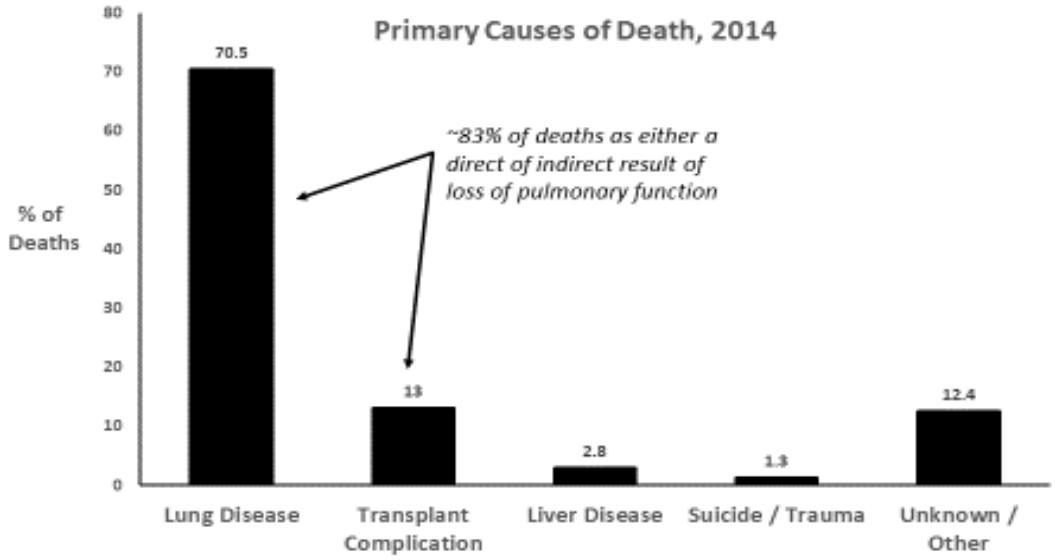
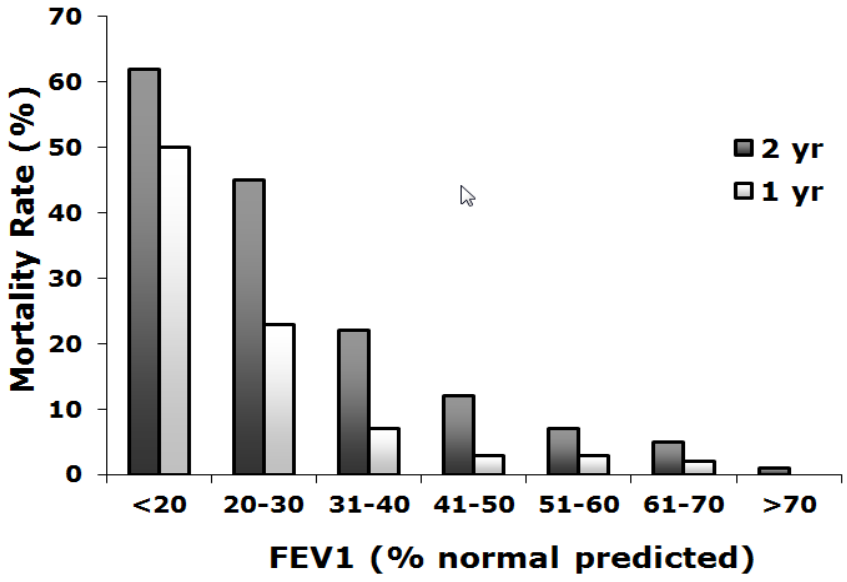
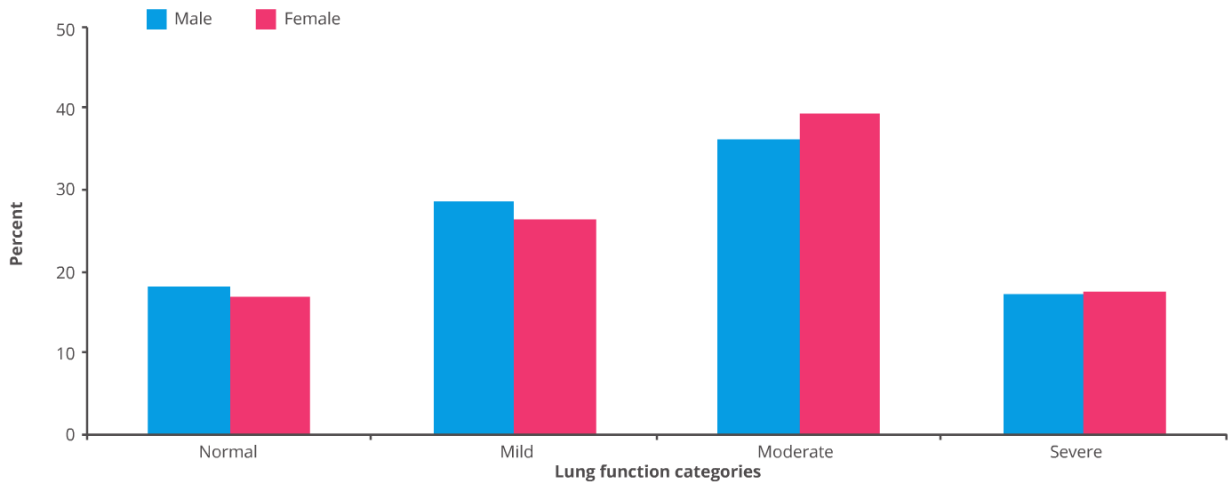


Figure 4: One-Year and Two-Year Mortality Rates According to FEV_1 Variable[61]



[59] Ibid.
[60] Cystic Fibrosis Foundation Patient Registry.
[61] Eitan Kerem et al., "Prediction of Mortality in Patients with Cystic Fibrosis," *N Engl J Med* 326 (1992).

Figure 5: Respiratory status of adults (18 years of age and older) with CF, by sex, CF Canada, 2014[62]



Alternatively, the redefined qualification of FEV_1 is preferred in at least one other federal jurisdiction, the United States.

There are differences among federal disability benefit programs between Canada and the USA. Social Security Administration (SSA) programs in the United States have a different approach to defining disability in CF, more aligned with the physiologic status of the lung disease in CF.[63] The Supplemental Security Income Program (SSIP) and the Social Security Disability Insurance Plan (SSDIP) support income supplementation and not income taxation benefits. However, defining definitions for Americans are disease-specific.

The definitions of disability and the process for determining disability are the same for both SSP and SSDIP programs. For adults, the determination of disability is '*an inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or expected to last for a continuous period of not less than 12 months*.'[64]

[62] Cystic Fibrosis Canada, "The Canadian Cystic Fibrosis Registry - 2014 Annual Report".(Figure 19)
[63] Social Security Administration, "Disability Evaluation under Social Security," https://www.ssa.gov/disability/professionals/bluebook/.
[64] GS Wunderlich, Institute of Medicine Staff, and DP Rice, *Dynamics of Disability: Measuring and Monitoring Disability for Social Security Programs* (National Academies Press, 2002).

The Social Security Administration in the US will automatically approve a CF patient for disability benefits if prospective criteria for defining severity in cystic fibrosis are met.[65] The SSA disability benefits apply mainly to income supplementation, not taxation credits, which best represent the limitations caused by the impairments on 'substantial gainful activities' of employment. These are demonstrable objective qualifications, as distinct from the subjective assessments of activities of daily living by both Canadian patients and physicians.

The Americans also define disability by recording the frequency of lung infections and the inconveniences of hospitalizations and/or home parenteral (intravenous) antibiotics. Really it is an either/or definition situation. CF clinicians, who must first authorize that the patient meets the criteria, will rely on at least one of the following:

- *Poor breathing test*. Spirometry test results that show an FEV_1 equal to or less than a volume of between 1.45 and 2.05, depending on your height (Table 4). These are absolute values and not recorded as a percentage of normal predictive. So included is a height variable, but not weight for height (the BMI) nor age or gender.
- *Pulmonary exacerbations*. Recurring episodes of coughing up blood (hemoptysis), pneumonia, bronchitis, or respiratory failure that require medical attention. The episodes must occur every other month or at least six times per year. If hospitalized for more than 24 hours this will count as two exacerbations.
- *Chronic infections*. Chronic lung infection with increased bacterial infections recurring at least once every six months that require antibacterial treatment intravenously or by nebulizer.

- **Table 4:** Qualifying spirometry test results[66]

Height	**FEV_1(liters)**
5' or shorter	1.45
5'1"-5'2"	1.55
5'3"-5'4"	1.65
5'5"-5'6"	1.75
5'7"-5'8"	1.85
5'9"-5'10"	1.95
5'11" or taller	2.05

[65] "Social Security Disability & Cystic Fibrosis: Filing and Getting Benefits," Disability Secrets published by NOLO, http://www.disabilitysecrets.com/resources/social-security-disability-cystic-fibrosis-filing-and-get.
[66] Ibid.

Defining disability based on some fixed numerical criterion, such as the FEV_1, can prove exacting and an FEV1 slightly over the 40% cutoff can easily default a disabled CF adult into a situation of not qualifying. Also what seems unfortunate is that the criterion of FEV_1 only reflects a singular complication of CF, thereby ignoring the nutritional and gastrointestinal aspects of chronic CF. At this point in the discussion of CF disability it would seem important to recommend disease-specific criteria that accommodate all the dysfunctional aspects of CF. For Option 2 to be applied in Canada, one might expect the redefinition of CF disability to be based on specific and CF-unique combinations of parameters. Applying for the DTC is not disease specific. One final point is that a child with CF disability will fail to qualify as performing lung function testing is not standardized at pediatric ages under 6-12 years.

Option 3: What other options are available that might be preferred?

Other options are available that might be preferable to either maintaining the status quo or avoiding the exacting definitions of an FEV_1. Options include a systematic process of advocating on behalf of the CF patient – either by the patients or their healthcare providers. Advocacy must apply to chronic diseases in general with acceptance of those unique aspects of adults with CF.

Disability is currently defined in such a way as to deny eligibility for persons suffering with a chronic disease. Many other chronic disease-related disabilities that are both prolonged, severe, and progressive should have equal advantage to the DTC. Such diseases also have "hidden" disabling manifestations that are not simply visible physical handicaps, and that are not in any way related to speaking, hearing, walking, eliminating, feeding, and dressing. They do not necessarily limit activities of daily living. And for the many, none are necessarily affiliated with reduced mental functions necessary for daily life.[67] This poses a challenge to pursue reform through the suggested option of advocacy. Option 3 looks at other broader definitions of disability. Considerations include:

- Promoting to government the advantages of legislating a Disability Screening Questionnaire that is comparable to the Residual Functioning Capacity questionnaire available to CF adults in the USA;
- Developing acceptable criteria for disabling chronic diseases, inclusive of CF, that do not rely entirely on activities of daily living;

[67] "Disability Tax Credit Certificate - T2201-15e Information Sheet."

- Show patients how to advocate on their own behalf by offering personal descriptive materials appropriate to their own disabling disease.
- Regulate the involvement of private sector promoters of the disability application process.

In the US, the SSA will review applications for disability based on the Residual Functional Capacity (RFC), a disability determination requiring defined medical factors alone.[68] This is where, in the USA, disability is often reviewed given disease-specific criteria – cystic fibrosis being one of these diseases.[69] No disease specific allowance for the DTC is available to Canadians with CF. Canadian legislation is now proposing a similar Disability Screening Questionnaire (DSQ),[70] although mainly for Statistics Canada surveys for disability levels among the Canadian population. To the present there is not appeal option for the DTC if an adult with CF fails to meet the minimal qualifications under present guidelines – with the sole exception of appeals to the Tax Court of Canada. The RFC applies to CF if you live in the USA; the DSQ is mainly a statistical definition without formally recognizing the disability that qualifies in CF. (See Appendix 1)

There are numerous examples of chronic diseases, other than pulmonary conditions such as cystic fibrosis, bronchiectasis and chronic obstructive lung diseases. From the routine perspective of a treating physician, none of these necessarily inhibit activities of daily living, and many do not have specific life-sustaining options. They should however equally require the financial advantage of the disability tax credit.

As distinct from visible or physical disabilities, those persons with chronic diseases could be assessed by unique criteria without requiring limitations of activities of daily living. Criteria for disabling chronic disease could include:

- an illness of a duration greater than one year, which in reality is usually lifelong
- a requirement for interdisciplinary medical care
- a disease that is progressive, severe, and ultimately fatal.

[68] "What Is Your Residual Functional Capacity?," Martindale & Nolo, http://www.alllaw.com/articles/nolo/disability/rfc-social-security.html.
[69] Social Security Administration.
[70] Chantal Grondin, "Canadian Survey on Disability, 2012: A New Survey Measure of Disability: The Disability Screening Questions (Dsq)," http://www.statcan.gc.ca/pub/89-654-x/89-654-x2016003-eng.pdf.

To help clarify the definition of disability, there are government-issued guides available and of equal benefit. These include: a guide (in England) to the assessment criteria for PIP;[71] The Social Security Tribunal: A Self-Help Guide for Canada Pension Plan Disability Approvals[72] and the Persons with Disabilities Application Guide: BC Disability Benefits[73], the two latter as published by the British Columbia Disability Alliance; and Tax Measures for Persons with Disabilities: Disability-Related Information, 2015.[74]

CF patients in Britain, in order to act as their own advocates, are best represented by the current position of England's CF Trust. Government issued guides of all the definitions required in the application are not available in Canada in the same way as in Britain. The Office for Disability Issues of Her Majesty's Government has published the Equality Act 2010 and, as part of this, a Guidance is available on matters to be taken into account in determining questions relating to the definitions of disability.[75] [76] This has been summarized in Appendix 2.

Disability Rights UK represents disabled people in England. Their mandate is to lead change and work for equal participation for all. They are comprised of leaders with diverse experiences of disability and health conditions from different communities. In addition to user-friendly guides to benefits, independent living, and careers, they also annually publish the acclaimed Disability Rights Handbook.[77] In England, the Department for Work and Pensions is responsible for most of the financial help available to disabled people. The entitlement for anyone who is disabled depends on the effect of the disability on that person's life. The Handbook, therefore, is a comprehensive guide to benefits for disabled people and in addition to social security benefits and tax credits. It covers practical help, services and other essential matters regarding care and

[71] Cystic Fibrosis Trust, "Cystic Fibrosis Trust - a Guide to the Assessment Criteria for Pip," https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/support-available/financial-support/personal-independence-payments/a-guide-to-the-assessment-criteria-for-pip.
[72] Disability Alliance BC and Community Legal Assistance Society, "The Social Security Tribunal: A Self-Help Guide for Canada Pension Plan Disability Appeals," http://www.disabilityalliancebc.org/docs/sst_tribunal_guide_revised_january_2016.pdf.
[73] Disability Alliance BC, "Persons with Disabilities (Pwd) Application Guide: Bc Disability Benefits," http://www.disabilityalliancebc.org/docs/pwd_application636002020661520667.pdf?LanguageID=EN-US.
[74] Canada Revenue Agency, "Tax Measures for Persons with Disabilities: Disability Related Information, 2015."
[75] "Equality Act 2010," ed. legislation.gov.uk (The National Archives, 2010).
[76] "Equality Act 2010 - Guidance on Matters to Be Taken into Account in Determining Questions Relating to the Definition of Disability," ed. HM Government Office for Disability Issues (2010).
[77] Ian Greaves, *Disability Rights Handbook: Edition 41 April 2016-April 2017* (London, UK: Disability Rights UK, 2016).

support services under the Equality legislation. For allied health care workers, the Handbook is the sole reference guide to all that applies to disability qualifications and benefit plans.

Patients can help themselves by promoting their own eligibility for disability benefits. The Cystic Fibrosis Trust in England has published an outline of CF patient care needs that allows the patient to personalize their application for disability.[78] The questions are generic, but the answers are patient-specific and relevant for those who can now feel that they have an opportunity to participate in defining their disease status fully. From this publication is a summary checklist that offers personalized input in the whole process (see Appendix 2).

How might non-government organizations (NGOs) and not-for-profit agencies assist to improve eligibility legislation for the DTC? Disability alliances exist in provinces and territories across Canada. In general, their focus is not on chronic disease definitions and certainly not on CF as one particular disease in need of disability assistance.

The Council of Canadians with Disabilities (CCD) is a national human rights organization of people with disabilities working for an inclusive and accessible Canada.[79] Table 5 is a compilation of CCD agencies that are representative of disabled Canadians.

Table 5: Council of Canadians with Disabilities

CCD members include:

- 9 Provincial Cross Disability Organizations
    - Disability Alliance BC (DABC)
    - Alberta Committee of Citizens with Disabilities (ACCD)
    - Saskatchewan Voice of People with Disabilities (SVOPD)
    - Manitoba League of Persons with Disabilities (MLPD)
    - Citizens with Disabilities – Ontario
    - Confédération des Organismes de personnes handicapées du Québec (COPHAN)
    - Nova Scotia League for Equal Opportunities (NLSEO)

[78] Cystic Fibrosis Trust, "Cystic Fibrosis: A Lifelong Challenge," www.cysticfibrosis.org.uk.
[79] Council of Canadians with Disabilities, "A Modernised Court Challenges Program of Canada: A Perspective from the Council of Canadians with Disabilities," http://www.ccdonline.ca/en/humanrights/promoting/A-Modernized-CCD-19April2016.

    - PEI Council of People with Disabilities (PEICOD)
    - Coalition of Persons with Disabilities – Newfoundland and Labrador (COD-NL)
- 1 Associate Member
    - NWT Disabilities Council
- 7 National Consumer-Controlled Organizations
    - Alliance for Equality of Blind Canadians (AEBC)
    - Canadian Association of the Deaf (CAD)
    - DisAbled Women's Network / Réseau d'action des femmes handicapées (DAWN-RAFH) Canada
    - National Educational Association of Disabled Students (NEADS)
    - National Network for Mental Health (NNMH)
    - People First of Canada (PFC)
    - Thalidomide Victims Association of Canada (TVAC)

Source: Council of Canadians with Disabilities[80]

CCD's work in the area of Human Rights and Equality Rights. They "*apprise judges, lawmakers and other decision-makers about how disability must be taken into consideration in all areas of community life, thus ensuring Canadians with disabilities have full enjoyment of their human and equality rights."*[81] Through CCD, people with disabilities advise, critique, intervene, liaise and partner to improve access and inclusion in Canada. *CCD "has been sharing its vision of how to achieve an accessible and inclusive Canada with private and public decision-makers responsible for the key systems of society, such as the physical and cultural environment, transportation, income and benefits, employment, health and social services."* The CCD promises to continue advancing measures, such as the refundable DTC, designed to improve the social and economic conditions of people with disabilities. Also, required are proactive advocacy organizations who promote improving the personal definitions of disabilities for chronic diseases.

Albertans have an additional resource for assistance. The Premier's Council on the Status of Persons with Disabilities, as enacted in 1988 and renewed in 2000, could be an important vehicle

[80] "Council of Canadians with Disabilities," http://www.ccdonline.ca/en/.
[81] Ibid.

for change to the Province's contributions to the Disability Tax Credit.[82] The Council's annual reports have not tabled motions on the DTC and therefore it remains an open issue.

Private sector consultants, only if regulated, may play an important role. Clients eligible for the Disability Tax Credit can seek assistance with the application process. Private-sector consultants (Promoters) charge a contingency fee (as high as 20% to 33% of the tax credit refund[83]) and given the significant financial gains to the promoter, they have a major incentive to recruit disabled Canadians. Promoters make representation to physicians for successful completion of the DTC application. These promoters are currently unrestricted.

The Canada Revenue Agency held public consultations in November and December 2014 to obtain input from stakeholders about the maximum allowable fee and who if any promoters should be exempt from the reporting requirements. The consultations included professional associations, tax preparers, medical practitioners, lawyers, persons with disabilities and their families, as well as associations representing persons with disabilities.

On May 29, 2014, during the former Conservative majority government, a private member's bill (Cheryl Gallant, MP Renfrew-Nipissing-Pembroke), the *Disability Tax Credit Promoters Restrictions Act* C-462, was enacted.[84] It awaits implementation under the new elected Liberal government. Suggested are a fixed maximum dollar fee amount, a base dollar amount adjusted for each additional taxation year amended, or a graduated fee amount based on the size of the refund.[85] Additionally, the DTC Certificate, T2201-1,[86] should require acknowledgment of the involvement of a fee-based consultant. Any on-line or in-person consultation process must ensure that persons with disabilities are not paying excessive fees for guided assistance in completing the DTC request forms.

The Governor in Council sets the maximum dollar fee amount for the DTC promoter. It is important to assume that the fee will not be based on the contingency of a successful application and that the fee is graduated to control the excessive revenues for any retroactive tax credit. The

[82] Alberta Human Services Government of Alberta, "Premier's Council on the Status of Persons with Disabilities," http://www.humanservices.alberta.ca/department/premiers-council.html.
[83] McFeat, "Tax Season 2015: The Disability Tax Credit and the Push for Fee Limits".
[84] "Disability Tax Credit Promoters Restrictions Act, Sc 2014, C 7," (CanLII, 2014).
[85] "Tax Season 2015: The Disability Tax Credit and the Push for Fee Limits".
[86] "Disability Tax Credit Certificate - T2201-1."

Minister of Revenue will create a penalty notification form to be submitted by any promoter charging or accepting a fee that exceeds the maximum fee allowable under the Act.

C-462 received royal assent on May 29, 2014. The public consultation process concerning the drafting of the relevant Regulations took place in the fall of 2014. The Draft Regulations are expected to be published in early to mid-2016, and they will be open for public and industry comment at that time. The actual requirements of the Act will probably not be published until late 2016 early 2017 when the Regulations are finalized, and the law comes into effect.

Suggested goals of the Act are to:

- bridge the regulatory process with the Provinces – the federal and provincial governments have shared obligations to support the DTC.
- publish any proposed regulations in the Canada Gazette to allow stakeholders (both promoters and the disabled clients) the opportunity to comment on the draft regulations before they are finalized.
- establish an appeal process for disabled clients to seek retribution if the newly regulated promoter exceeds allowable limits on fees.
- ensure that all DTC Certificates indicate if a promoter has been contracted to support the process of the DTC Certificate. The in-house "medically-trained" professionals of many promoter firms should be regulated and audited in much the same fashion as private physicians responsible for qualifying a disabled client.
- approve of a regulatory process that involves the disability promoters' professional group, the Association of Canadian Disability Benefit Professionals (ACDBP). The ACDBP must thereby represent all Promoters and their firms in Canada, something that at present they do not do. The ACDBP will also accredit the professional education of all promoters. There must be some form of sponsored continuing education for updating all promoters.
- ensure that the DTC Promoters Restriction Act includes an audit process that reports directly to Revenue Canada and the Minister of Revenue.

This Act comes into force on a day to be fixed by order of the Governor in Council. The next opportunity to provide input on the proposed regulations will be when they are pre-published in Part I of the *Canada Gazette*, which is anticipated in the latter half of 2016. At that time stakeholders will have the chance to comment on the draft regulations before they are finalized.

So What Now? How Might One Agree to Proceed to Amend the Current DTC Eligibility Criteria?

"*There is the need for the tax system to deal in a humane and compassionate manner with Canadians with disabilities by improving the policies and the administration of the income tax system generally -- and the DTC in particular*."[87] The Parliament of Canada, in 2002, convened the Standing Committee on Human Resources Development and the Status of Persons with Disabilities who subsequently published its report *Tax Fairness for Persons with Disabilities*.[88] A similar review process published *Disability Tax Fairness: the Report of the Technical Advisory Committee for Persons with Disabilities*.[89]

Accessibility remains a priority. Table 6 lists the accessibility legislation of both Canadian and international jurisdictions. Only three provinces have approved such legislation on behalf of disabled Canadians, and these articles of disability law date back at least ten years and are not yet uniformly adopted by all provinces and territories.

To eliminate systemic barriers and deliver equality of opportunity to all Canadians living with disabilities, the Government announced, in its 2016 federal budget, that monies would be set aside to develop a Canadians with Disabilities Act.[90] The government plan is to consult with provinces, territories, municipalities and stakeholders to introduce the Canadians with Disabilities Act. The budget allocated $2 million over two years, starting in 2016–17, to support the full participation of Canadians with disabilities in this process.

Rick Hansen, the Canadian Paralympian, activist for disability legislation, and CEO of the Rick Hansen Foundation, said in a statement that promising money for the creation of a Canadians with Disabilities Act is a positive step. "*An Act itself won't solve everything right*

[87] Longfield.
[88] "House of Commons Committees - Huma (37-2) - Tax Fairness for Persons with Disabilities ", (2002), accessed November 14, 2015, http://www.parl.gc.ca/HousePublications/Publication.aspx?DocId=1032189&Language=E&Mode=1&Parl=37&Ses=2#top.
[89] Sherri Torjman and Robert D. Brown, "Disability Tax Fairness: Report of the Technical Advisory Committee on Tax Measures for Persons with Disabilities," http://worthwhile.typepad.com/files/disability_tax_fairness.pdf.
[90] Government of Canada Minister of Finance, "Growing the Middle Class: Budget 2016," ed. Department of Finance (2016).

away; there are still many physical and attitudinal barriers to find solutions for; but by working together, we can start to address this urgent need and make sure that people with disabilities are living to their full potential."[91]

Table 6: Accessibility Legislation, Canada and International Jurisdictions[92]

United Nations, 2006	*Convention on the Rights of Persons with Disabilities*[93]
The United States, 1990	*Americans with Disabilities Act of 1990*[94] *and Americans with Disabilities Amendment Act or 2008* [95]
Australia, 2008	*DDA: Disability Discrimination and Other Human Rights Legislation Amendment Act*[96]
Canada, 2016	*Growing the Middle Class, Budget 2016* [97] *with the announcement of a National Disabilities Act*
Province of Ontario, 2005	*Accessibility of Ontarians with Disabilities Act*[98]
Province of Manitoba, 2013	*The Accessibility for Manitobans Act*[99]
Province of Quebec, 2015	*Loi assurant l'exercice des droits des personnes handicapées en vue de leur intégration scolaire, professionnelle et sociale*[100]

[91] Klingbeil.
[92] Employment and Social Development Canada.
[93] "Convention on the Rights of Persons with Disabilities," United Nations, http://www.un.org/disabilities/convention/conventionfull.shtml.
[94] "Americans with Disabilities Act of 1990 - Public Law No. 101-336 - July 26, 1990," ed. 101st United States Congress, enacted by Senate and House of Representatives of the United States of America in Congress Assembled (1990).
[95] "Americans with Disabilities Act Amendments Act of 2008," in *PL 110-325 (S3406) - September 25, 2008*, ed. Senate and House of Representatives of the United States of America in Congress assembled (2008).
[96] Australia Federal Register of Legislation, "Disability Discrimination Act 1992," (2016).
[97] Minister of Finance.
[98] Government of Ontario, "Accessibility for Ontarians with Disabilities Act, 2005, S.O, Chapter 11," (2005).
[99] Legislative Assembly of Manitoba, "The Accessibility for Manitobans Act," (2013).
[100] Quebec Office des personnes handicapees, " Loi Assurant L'exercice Des Droits Des Personnes Handicapées En Vue De Leur Intégration Scolaire, Professionnelle Et Sociale," (2015).

It is now appropriate for Canada to include updated definitions of disabilities as they apply to persons with chronic diseases. The Americans with Disabilities Act might represent to our federal government a framework for a similar legislated Act here in Canada.

On July 26, 1990, President George H.W. Bush signed into law the Americans with Disabilities Act (ADA).[101] The ADA defines disability as an impairment, physical or mental, that substantially limits one or more activities of daily living. The ADA was intended to incorporate health and wellness messages into all business mission statements, be responsive to employees' health needs and lifestyles, encourage personal ownership of health status, and design programs accessible to all employees.

In 2008, Congress passed the Americans with Disabilities Act Amendments Act (ADAAA) placing emphasis on broad standards when determining whether an individual is disabled. The ADA used semantics that narrowed the eligibility interpretation, and the ADAA instructed the Courts to be as inclusive as possible under the maximum interpretation of the disability criteria. This included mitigating and corrective treatments, medications or medical devices that are now no longer irrelevant in determining whether an American is protected under the ADA.

The ADA is nonspecific about the etiology of the disability, and the Equal Employment Opportunity Commission (EEOC),[102] the federal agency that enforces this and other employment discrimination laws and precludes discrimination in the workplace, provides examples of both single-gene diseases such as muscular dystrophy, and complex disorders like multiple sclerosis, that substantially limit major life activities. Cystic fibrosis would be included by these criteria – single gene and complex disorders. The EEOC acknowledges the significant AADA changes to the definition of disability under the ADA with the mandate that "*the definition of disability be construed broadly"*.[103]

There are usually three interpretations of ways the ADA/ADAAA Acts focus on disability. The first and most significant way to prove disability is by demonstrating "[a] *physical or mental impairment that substantially limits one or more of the major life activities of such individual*."

[101] "Americans with Disabilities Act of 1990 - Public Law No. 101-336 - July 26, 1990."
[102] Equal employment USA Office of Civil Rights, "Equal Employment Opportunity," http://www.gsa.gov/portal/content/101013.
[103] "Information About the Americans with Disabilities Act Amendments Act (Adaaa) of 2008," https://www.eeoc.gov/laws/statutes/adaaa_info.cfm.

The elements in this definition, "*physical or mental impairment*," "*substantially limits*," and "*major life activities*", are all broadly defined to enhance coverage under the law.

"*Having a record of such an impairment*" is a second way to demonstrate disability.

The third way that a person can be deemed disabled for purposes of the ADA is "[b]*eing regarded as having such an impairment… whether or not the impairment limits or is perceived to limit a major life activity*."[104]

The Americans with Disabilities Act Amendments Act of 2008 emphasizes that the definition of disability should be construed for broad coverage of individuals to the maximum extent permitted by the terms of the ADA and generally shall not require extensive analysis. The Act makes important changes to the definition of the term "disability. The effect of these changes is to make it easier for an individual seeking protection under the ADA to establish that he or she has a disability within the meaning of the ADA. The Act retains the ADA's basic definition of "disability" as an impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment. However, it changes the way that these statutory terms should be interpreted in several ways.

Other laws address barriers to access to health care and health insurance, including HIPAA (Health Insurance Portability and Accountability Act), GINA (the Genetic Information Nondiscrimination Act of 2008), and most important, the Affordable Care Act, which prohibits discrimination in coverage and benefits based on health condition, whether already symptomatic or simply a predisposition and regardless of etiology. Some gaps in protection against disadvantaging individuals on the basis of genetic information remain, for example, in ensuring access to life, disability, and long-term care insurance. However, it is to the ADA that individuals who are symptomatic as a result of genetic variation must turn to address their needs and to challenge adverse treatment in employment.

Canada is now canvassing for public opinion about new legislation prohibiting discrimination against genetic variation [Genetic Non-Discrimination Act[105] and Bill S-201,

[104] "Regulations to Implement the Equal Employment Provisions of the Americans with Disabilities Act, as Amended - a Rule by the Equal Employment Opportunity Commission on 03/25/2011," https://federalregister.gov/a/2011-6056.

[105] Robert Oliphant, "Genetic Non-Discrimination Act - Bill S-201: An Act to Prohibit and Prevent Genetic Discrimination," ed. Forty-second Parliament First Session, 64-65 Elizabeth II, 2015-16 (Parliament of Canada, 2016).

currently proposed by Rob Oliphant, Liberal MP], which will add "genetic characteristics" as a prohibited ground of discrimination under the *Canadian Human Rights Act*.[106]

Conclusion

The proposed Canadians with Disabilities Act might be best advised to take either a prescriptive or an outcome-based approach to its legislation. Even though a performance-based regulatory system is preferred, it is the Act itself that should carry forward the issues of adults with CF to the DTC regulatory body, namely the Canada Revenue Agency.

With a more prescriptive approach, the legislation could provide authority for the Government of Canada to use regulations to establish detailed accessibility standards in areas of federal jurisdiction. It would describe the process or processes that the Government would use to develop the accessibility standards, as well as the areas or activities to which the standards would apply. And then it would describe compliance measures that the Government would use to ensure the accessibility standards have been implemented appropriately.

With an outcome-based approach, the legislation could set accessibility objectives that organizations would then try to achieve. With this approach, the legislation could enable collaborative processes for organizations to move forward with revised disability legislation. Required outcomes and levels of performance would be written into the legislated regulation.

Prescriptive regulations detail the design and process of legislative regulations about the DTC as applied to adults with cystic fibrosis. It defines how activities are to be undertaken. In contrast, outcome-based regulations are performance-based allowing the disabled community of Canada decide for itself how to achieve innovative results. It is this latter choice that is preferred, allowing for more accountability and better cost management because of the active participation of the CF community in the regulatory process. This will allow for regulated systems to identify outcomes that will allow for considerable flexibility. The CF community can then determine how to undertake the functions of the DTC and achieve the outcomes it desires.

"*Priority should be given to expenditure programs rather than tax measures to target new funding where the need is greatest. The Committee recognizes that the development of such programs would involve consultations with provincial and territorial governments and the*

[106] "Bill S-201: Background " http://roliphant.liberal.ca/page/bill-s-201-background/.

disability community".[107] Is this not still a priority that the current federal Liberal government should undertake. Might this then be a priority for the newly proposed Canadians with Disabilities Act?[108]

Andy Scott, M.P. for Fredericton-York-Sunbury, chaired Federal Task Force on Disability Issues, and his committee of four published the Equal Citizenship for Canadians with Disabilities – The Will to Act.[109] He is often quoted that:

- For persons with disabilities normal activities bring extraordinary costs that are involuntary.
- Some of these costs are general and intangible and others can be supported by receipts for expenditures.
- Tax recognition of these costs is not a subsidy based on sympathy or charity but fair tax treatment.
- Tax recognition of disability-related costs should encourage, not discourage, the employment of persons with disabilities.
- The costs associated with disability are more onerous when borne by individuals with limited income.
- The costs associated with disability are not limited to those with taxable income.

These are the assumptions that should shape going forward toward a more equitable policy on improving access for the Disability Tax Credit on behalf of adults with cystic fibrosis.

[107] Torjman and Brown.
[108] Employment and Social Development Canada.
[109] M.P. Chair Andy Scott et al., "Equal Citizenship for Canadians with Disabilities - the Will to Act," ed. Federal Task Force on Disability Issues (Government of Canada, 1996).

Appendix 1: Comparison of the Residual Functional Capacity Assessment Tool

And the Disability Screening Questionnaire

The RFC[110] *"represents the most that you can do despite the limitations caused by your impairment(s). If you have more than one impairment, the SSA will consider all of the limitations or restrictions resulting from all of your impairments (including severe and nonsevere impairments) in assessing your RFC. The SSA bases its assessment of RFC on all of the relevant evidence.*

For example, the SSA will look at the medical history, clinical signs and laboratory results, effects of treatment, effects of symptoms, and gather opinions from doctors regarding what can still be done despite the impairment, reports of daily activities, and possibly evidence from family, friends, or teachers. In assessing your RFC, the SSA must address both your exertional and nonexertional limitations and restrictions. There are seven strength demands – ability to sit, stand, walk, lift, carry, push, and pull. The decision about allowing the disability application is based on the classifications of the employment as sedentary, light, medium, heavy, and very heavy.

The SSA will then evaluate whether you can adjust to doing other jobs by considering "vocational" factors such as your age, education, and work experience in combination with your RFC. If the SSA determines that you can do other jobs (and such jobs exist in significant numbers in the national economy), then you will be found not disabled. However, if the SSA finds that your RFC and vocational factors prevent you from adjusting to other jobs, you will be found disabled and awarded disability benefits through what's called a medical-vocational allowance."

The DSQ[111] *"provides a measure based on the social model of disability which takes into account activity limitations to identify a disability. The intention is to include the DSQ in general population surveys to allow comparisons of people with and without a disability. This measure is useful in developing programs to help improve social participation for persons with a disability. Inclusion of the DSQ on general population surveys, as well as on the Canadian Survey on*

[110] "What Is Your Residual Functional Capacity?".
[111] Statistics Canada, "A New Survey Measure of Disability: The Disability Screening Questioons (Dsq)," http://www.statcan.gc.ca/pub/89-654-x/89-654-x2016003-eng.pdf.

Disability, will facilitate analyses, and will shed light on the situation faced by persons with a disability, and more importantly, on those whose daily activities are limited

The DSQ can also, although they were not created for that purpose, produce a measure of functional health — estimates of the prevalence of difficulties related to vision, hearing, mobility, flexibility, dexterity, pain, learning, memory, mental health, and development. But most importantly, it can determine how many people are limited in their daily activities owing to these difficulties or health problems. These are people who face barriers and may not have the help they need to participate in society fully."

Appendix 2: Guidance on Matters to be taken into Account in Determining Questions Relating to the Definition of Disability

As abstracted from the Equality Act 2010.[112]
(Compared to the Income Tax Act and definitions as applied to the DTC)

The Equality Act defines a disabled person as a person with a disability. A person has a disability for the purposes of the Act if he or she has a physical or mental impairment and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. The term **mental or physical impairment** should be given its ordinary meaning. It is not necessary for the cause of the impairment to be established, nor does the impairment have to be the result of an illness. Whether a person is disabled for the purposes of the Act is generally determined by reference to the effect that an impairment has on that person's ability to carry out normal day-to-day activities.

Equality Act 2010	**Income Tax Act on DTC**
This means that, in general: the person must have an impairment that is either physical or mental; the impairment must have adverse effects which are **substantial**; the substantial adverse effects must be **long-term**; and the long-term substantial adverse effects must be effects on normal day-to-day activities. It is the impairment, and not the disability, that must be substantial and long-term. The definition is not inclusive of the term progressive.	**Substantial** must be more than minor or trivial, and the adverse impact(s) of the impairment(s) must be substantial **Long-term** is referred to as progressive conditions treated as impairments with a substantial adverse impact(s).
A disability can arise from a wide range of **impairments** which can be: impairments with fluctuating or recurring effects; progressive; and organ specific, including respiratory conditions. [The illnesses listed are even more inclusive of many other conditions. Cystic fibrosis in particular was not included.] Other impairments include auto-immune disorders, developmental disorders, mental health conditions, mental illnesses themselves, and body injuries.	**Impairments** must be such that, even with therapy and the use of appropriate devices and medication, the client is restricted substantially all of the time (at least 90% of the time).

[112] "Equality Act 2010."

The cause of the impairment may be hard to establish. It may not always be possible, nor is it necessary, to categorize a condition as either a physical or a mental impairment. It is not necessary to consider how an impairment is caused, even if the cause is a consequence of a condition which is excluded. It is the effect of the impairment and not its cause. The disability can be either a manifestation of the impairment or a consequence of the impairment. It is important to remember that not all impairments are readily identifiable. While some impairments, particularly visible ones, are easy to identify, there are many which are not so immediately obvious, for example some respiratory and nutritional health conditions, including CF, mental health conditions and learning disabilities.	
The Act does not define what is to be regarded as a '**normal day-to-day activity**'. In general, day-to-day activities are things people do on a regular or daily basis. Examples include shopping, reading and writing, having a conversation or using the telephone, watching television, getting washed and dressed, preparing and eating food, carrying out household tasks, walking and travelling by various forms of transport, and taking part in social activities. Normal day-to-day activities can include general work-related activities, and study and education-related activities, such as interacting with colleagues, following instructions, using a computer, driving, carrying out interviews, preparing written documents, and keeping to a timetable or a shift pattern. The term 'normal day-to-day activities' is not intended to include activities which are normal only for a particular person, or a small group of people. A normal day-to-day activity is not necessarily one that is carried out by a majority of people. What cannot be said to be normal for most	**Normal day-to-day activities** as basic activities of daily living' which implies speaking, hearing, walking, eliminating (bowel and bladder functions), feeding, dressing and mental functions necessary for everyday life.

people would nevertheless be considered to be normal day-to-day activities. Also, whether an activity is a normal day-to-day activity should not be determined by whether it is more normal for it to be carried out at a particular time of day. In considering the ability of a child aged six or over to carry out a normal day-to-day activity, it is necessary to take account of the level of achievement which would be normal for a person of a similar age. Where a person is receiving treatment or correction measures for an impairment, the effect of the impairment on day-to-day activities is to be taken as that which the person would experience without the treatment or measures. Normal day-to-day activities also include activities that are required to maintain personal well-being or to ensure personal safety, or the safety of other people. Account should be taken of whether the effects of an impairment have an impact on whether the person is inclined to carry out or neglect basic functions such as eating, drinking, sleeping, keeping warm or personal hygiene; or to exhibit behavior which puts the person or other people at risk. An impairment may not directly prevent someone from carrying out one or more normal day-to-day activities, but it may still have a substantial adverse effect on how the person carries out those activities. For example, an impairment might make the activity more than usually fatiguing so that the person might not be able to repeat the task over a sustained period of time. Some impairments may require the person to undertake certain activities, or functions at such frequent intervals that they adversely affect the ability to carry out normal day-to-day activities.	
An impairment might not have a substantial adverse effect on a person's ability to undertake a particular day-to-day activity in isolation. The	**Cumulative** and **substantial** equates to **inordinate amount of time** which usually equals three times the normal

cumulative effect of an impairment considers whether its effects on more than one activity, when taken together, could result in an overall substantial adverse effect. For example, a person whose impairment causes breathing difficulties may, as a result, experience minor effects on the ability to carry out a number of activities such as getting washed and dressed, going for a walk or travelling on public transport. But taken together, the cumulative result would amount to a substantial adverse effect on his or her ability to carry out these normal day-to-day activities.

The cumulative effect of more than one impairment should also be taken into account when determining whether the effect is long-term. The examples of what it would, and what it would not, be reasonable to regard as substantial adverse effects on normal day-to-day activities are indicators and not tests. They do not mean that if a person can do an activity listed then he or she does not experience any substantial adverse effects: the person may be affected in relation to other activities, and this instead may indicate a substantial effect. Alternatively, the person may be affected in a minor way in a number of different activities, and the cumulative effect could amount to a substantial adverse effect.

Meaning of '**substantial adverse effect**' is one that is more than a minor or trivial effect. When assessing whether the effect of that impairment is substantial. It should be compared with the time it might take a person who did not have the impairment to complete an activity. Another factor to be considered when assessing whether the effect of an impairment is substantial is the way in which a person with that impairment carries out a normal day-to-day activity. The comparison should be with the way that the person might be expected to time needed to complete the same activity by a person who does not have the impairment.

Markedly or **significantly restricted** implies the activity to be restricted substantially all of the time (at least 90% of the time) even with therapy (other than therapy to support a vital function) and the use of appropriate devices and medication.

carry out the activity compared with someone who does not have the impairment.	
The Act states that, for the purpose of deciding whether a person is disabled, a **long-term effect** of an impairment is one: which has lasted at least 12 months; or where the total period for which it lasts, from the time of the first onset, is likely to be at least 12 months; or which is likely to last for the rest of the life of the person affected. The substantial adverse effect of an impairment which has developed from, or is likely to develop from, another impairment should be taken into account when determining whether the effect has lasted, or is likely to last at least twelve months, or for the rest of the life of the person affected. The cumulative effect of related impairments should be taken into account when determining whether the person has experienced a long-term effect for the purposes of meeting the definition of a disabled person.	**Prolonged or long-term** applies to effects that lasted at least 12 months or are likely to last at least 12 months, or are likely to last the rest of that client's life (if currently the duration is less than 12 months).
The meaning of '**likely'** is relevant when determining: whether an impairment has a long-term effect; whether an impairment has a recurring effect; whether adverse effects of a progressive condition will become substantial; or how an impairment should be treated for the purposes of the Act when the effects of that impairment are controlled or corrected by treatment or behavior. In these contexts, 'likely', should be interpreted as meaning that it could well happen.	
In regard to **recurring or fluctuating effects** the Act states that, if an impairment has had a substantial adverse effect on a person's ability to carry out normal day-to-day activities but that effect ceases, the substantial effect is treated as continuing if it is likely to recur. Conditions with effects which recur only sporadically or for short periods can still qualify as impairments for the purposes of the Act, in respect of the meaning of	

‘long-term’. Some impairments with recurring or fluctuating effects may be less obvious in their impact on the individual concerned than is the case with other impairments where the effects are more constant. If the substantial adverse effects are likely to recur, they are to be treated as if they were continuing. If the effects are likely to recur beyond 12 months after the first occurrence, they are to be treated as long-term. It is not necessary for the effect to be the same throughout the period which is being considered in relation to determining whether the ‘long-term’ element of the definition is met. A person may still satisfy the long-term element of the definition even if the effect is not the same throughout the period. It may change: for example activities which are initially very difficult may become possible to a much greater extent. The effect might even disappear temporarily.	
The term ‘**likely to recur**’ must take into account If medical or other treatment is likely to permanently cure a condition and therefore remove the impairment, so that recurrence of its effects would then be unlikely even if there were no further treatment. However, if the treatment simply delays or prevents a recurrence, and a recurrence would be likely if the treatment stopped, as is the case with most medication, then the treatment is to be ignored and the effect is to be regarded as likely to recur. It is possible that the way in which a person can control or cope with the effects of an impairment may not always be successful. If there is an increased likelihood that the control will break down, it will be more likely that there will be a recurrence. That possibility should be taken into account when assessing the likelihood of a recurrence.	

Appendix 3: Enabling Persons with Cystic Fibrosis to Better Qualify for the Disability Tax Credit

Please complete this questionnaire with as much detail about your cystic fibrosis. Make as much room as you need to answer these questions fully. Be sure to provide your full name, date of birth, mailing address, email address, and contact phone numbers.

You need to show that your disability requires your full attention throughout the daytime and night in regard to your daily routine of health care expectations. Be open and honest, and include everything you believe to be pertinent

A. Treatment / Medication Care Needs

1. Physiotherapy? Y/N

    No. times daily

    No. minutes each time

    Does anyone help with your physiotherapy treatments? Y/N

    Why and in what way?

2. Antibiotics? Y/N

    No. chest infections in last six months

    Daily oral antibiotics on a long-term basis? Y/N

    No. times daily?

    Daily nebulized antibiotics? Y/N

    No. times daily

    Time duration to administer?

    Does anyone help with your oral antibiotic treatments? Y/N

    Why and in what way?

    Intravenous antibiotic therapy at home on a periodic as needed basis (i.e. HPTP)? Y/N

    No. courses of iv antibiotics in past six months?

    List of all antibiotics prescribed intravenously

    For each course of treatment, no. times daily?

    Time duration per day?

    No. consecutive days of treatment per course of therapy? List separately

    Does anyone help with your intravenous at home treatments? Y/N

Why and in what way?

Intravenous antibiotic therapy administered on a routine basis (i.e. one week per month)? Y/N

Type of antibiotic and frequency?

Does anyone help with your routine iv antibiotic treatments? Y/N

Why and in what way?

3. Other treatments? Y/N

Nebulized antibiotic therapy? Y/N

Types, no. times daily, time duration per day?

Inhalers and other nebulized medications?

Types, no. times daily, time duration per day?

Does anyone help with your nebulized treatments? Y/N

Why and in what way?

B. Nutritional care?

1. Pancreatic enzyme supplements? Y/N
2. Vitamin supplements? Y/N
3. Nutritional caloric supplements? Y/N

Types, no. of times per day, time duration per day?

4. Enteral tube feedings? Y/N

No. of cans per day?

Types, no. times per day, time duration?

C. Mobility Needs?

1. Are you adult and over age 18? Y/N
2. If under age 18, does a parent / guardian/ caregiver assist? Y/N
3. How far can you walk unassisted (without oxygen, canes, or walkers)?

3.1. When feeling well? When feeling unwell?

4. How far can you walk with the assistance of oxygen, canes, or walkers?

4.1. When feeling well? When feeling unwell?

5. Have you been provided with a wheelchair? Y/N

6. If mobility is restricted, is it because of coughing, breathlessness, chest tightness, CF arthropathy (sore/stiff joints)? Specify all that apply.
7. If you require mobility assistance (oxygen, canes, or walkers), for how many days per month?

D. Additional care needs?

1. Do you require assistance with preparing / cooking meals? Y/N Please specify
2. Do you require assistance overnight while sleeping? Y/N Please specify
3. Do you have more than occasional epistaxis (nose bleeds)? Y/N Please specify
4. Do you have more than occasional hemoptysis (blood in sputum)? Y/N Please specify
5. Do either epistaxis or hemoptysis occur on a regular or frequent basis? Y/N Please specify

E. Does having CF require other extra care needs not specified above? Y/N Please specify

F. Can you think of anything else not mentioned above that you consider relevant? Y/N Please specify

As modified from Cystic Fibrosis: a lifelong challenge.[113]

[113] Cystic Fibrosis Trust, "Cystic Fibrosis: A Lifelong Challenge".

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