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SENATE SUBMISSION

EQUITABLE ACCESS TO TAX FAIRNESS FOR THE AUTISM COMMUNITY

February 1, 2018

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EXECUTIVE SUMMARY

Autism is a lifelong condition that impacts normal brain development leaving most individuals with communication problems, difficulty with typical social interactions and a tendency to repeat specific patterns of behaviour. Persons with autism and their families face more barriers in economic, educational and social spheres than those living without disability. Parents and caregivers carry the bulk of the financial and caregiving burden. One of the greatest concerns facing parents of children with autism and autistic adults is the uncertainty of the future. Autism Canada has heard from hundreds of Canadian families, and without exception, it is the futures of their children that are their greatest concern. One father writes:

> ***"Currently, we are impacted by the inability to secure our son's future. We are his sole social circle, we are his financial backers, we are his transportation – we are his life. My fears keep me awake at night. If we don't have something in place – a plan, a program, a support network – what will happen to my son when I'm gone? Institutionalized, neglected, or worse homeless, with no love or supports – I need peace of mind and he needs a future."***

Despite being one of the principal federal supports for individuals in Canada with severe and prolonged impairments, the Disability Tax Credit (DTC), as presently designed, does not address the needs of people with neurodevelopmental disorders like autism. Inconsistencies in application reviews by Canada Revenue Agency (CRA) staff lay a foundation for bleak financial outcomes for this vulnerable population.

A policy overhaul of the DTC, and broader disability policy in Canada, is long overdue. In this submission we present five recommendations:

1. The creation of a clear, transparent and informed application, review and appeals process
2. Clear, consistent and universally accepted classification criteria for disability
3. Uncoupling the Registered Disability Savings Plan (RDSP) from the DTC
4. Federal monitoring and evaluation of population-based disability data
5. Inclusion of the neurodevelopmental community on the Disability Advisory Committee

More broadly, it is time for Canada to consider new coordinated policy measures that guarantee improved access, independence, portability and support for individuals with autism.

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INTRODUCTION

Autism Canada launched a lengthy review when it was brought to our attention that an unprecedented number of applicants were being rejected by the Canada Revenue Agency for the Disability Tax Credit. The hundreds of stories received from autistics and families echoed an astonishingly clear message: the application and review process for the DTC lacks consistency and transparency, is plagued with inequality and is an onerous process barely justifying the efforts required to apply.

Doctors, psychologists, diagnosticians and clinicians from across the country support these statements, stating that they complete hundreds of DTC applications every year, of which a large proportion are rejected or returned requesting supplemental information. After providing this additional information, a sizable proportion is further rejected. The financial consequences of rejection are significant for families. When the DTC is rejected, not only does the family incur a host of expenses paid for only by after-tax dollars, but they will also not qualify for the Registered Disability Savings Plan. This combined disqualification places unjust financial hardship and stress on individuals and families.

UNDERSTANDING AUTISM

Autism is a complex neurodevelopmental disorder that impacts brain development causing most individuals to experience communication problems, difficulty with social interactions and a tendency to repeat specific patterns of behaviour. There is also a markedly restricted repertoire of activities and interests.

Sadly, there is great misconception that those with milder autism, otherwise known as higher functioning autism or Asperger's Syndrome, are less deserving of the DTC and its related tax benefits, but nothing could be further from the truth. "Milder" expressions of autism do not result in mild deficiencies in functioning. The challenges are associated with significant impairment in academic, vocational, and particularly social functioning. For all autistics, there are co-occurring medical conditions such as epilepsy, sleep disorders, gastrointestinal abnormalities, immune dysregulation and mental health issues like anxiety and depression, that further exacerbate the need for emotional and financial supports.

The DTC is one of the principal federal supports for individuals in Canada with severe and prolonged impairments. Administered by the Canada Revenue Agency, it is designed to provide tax relief for non-itemizable (or hidden) disability- or therapy-related costs. The credit can be claimed by the individual with the disability and can also be transferred to an eligible caregiver such as a parent, grandparent or sibling to claim on their tax return. Eligibility to the credit provides access to other important benefits such as the Registered Disability Savings Plan.

Yet, access to the DTC is inequitable. This submission aims to provide an overview of changes required to create and maintain equitable treatment regarding the DTC for those living on the autism spectrum and their families.

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BACKGROUND

Persons with autism face higher costs of living and additional barriers to financial security

One in 68 people are currently diagnosed with autism (Centers for Disease Control and Prevention, 2016). These individuals and their families face more barriers in economic, educational and social spheres than those living without disability (Prince, 2016). Canadians with severe mental and physical impairments are more likely to be living in low income and face some of the highest levels of unemployment, underpinned by low levels of educational attainment and barriers to participating in the labour force (Till, Leonard, Yeung and Nicholls, 2015; Wall, 2017). For example, 75 percent adults with a developmental disability were not working in 2012, and only half had completed high school (Zwicker, Zaresani and Emery, 2017).

Of those with higher functioning autism, 98 percent never married, and 76 percent were hospitalized or lived with their parents indefinitely (Tantam, 1991). Outcomes for children more severely impacted by autism are even worse. These lifelong impairments have huge impact on the prospects for the autistic individual, as well as repercussions within the family and society at large. The estimated lifetime costs of an autistic individual can be anywhere from $1.4 to $2.4 million depending on whether an intellectual disability is present or not. (Buescher, Cidav, Knapp & Mandell, 2014). These higher costs are somewhat borne by governments however many are not.

Autistic individuals and their families regularly need to supplement government services with privately accessed services, equipment, or program fees. These “extras” include specialized daycare, respite, tutors, personal support workers, more expensive utility and transportation costs (Mitra, Palmer, Kim, Mont and Groce, 2017), supplemental therapy hours, job and life coaches, specialized camps, therapy equipment, home renovations for safety or treatment reasons, allied health services such as speech-language therapy, occupational therapy, psychology, and specialized diets, etc. As well, as these direct costs, there are indirect costs. Autism impacts parents’ employment opportunities. Many parents give up their jobs and incomes in order to provide care, supervise in-home therapy, drive their children to multiple appointments, or be available at a moment’s notice when children are sent home from school or treatment programs. These direct and indirect costs are overwhelming for many, if not most, living with autism.

The Disability Tax Credit is an outdated disability policy instrument that no longer works in today’s landscape resulting in inequities in its implementation

Despite being one of the principal federal supports for individuals in Canada with severe and prolonged impairments, the DTC, as presently designed, does not meet the needs of many people with neurodevelopmental disorders such as autism.

Introduced in 1944 as a deduction for blind persons, the DTC was subsequently extended to individuals with severe disabilities. It was then converted to a non-refundable tax credit along with other disability-

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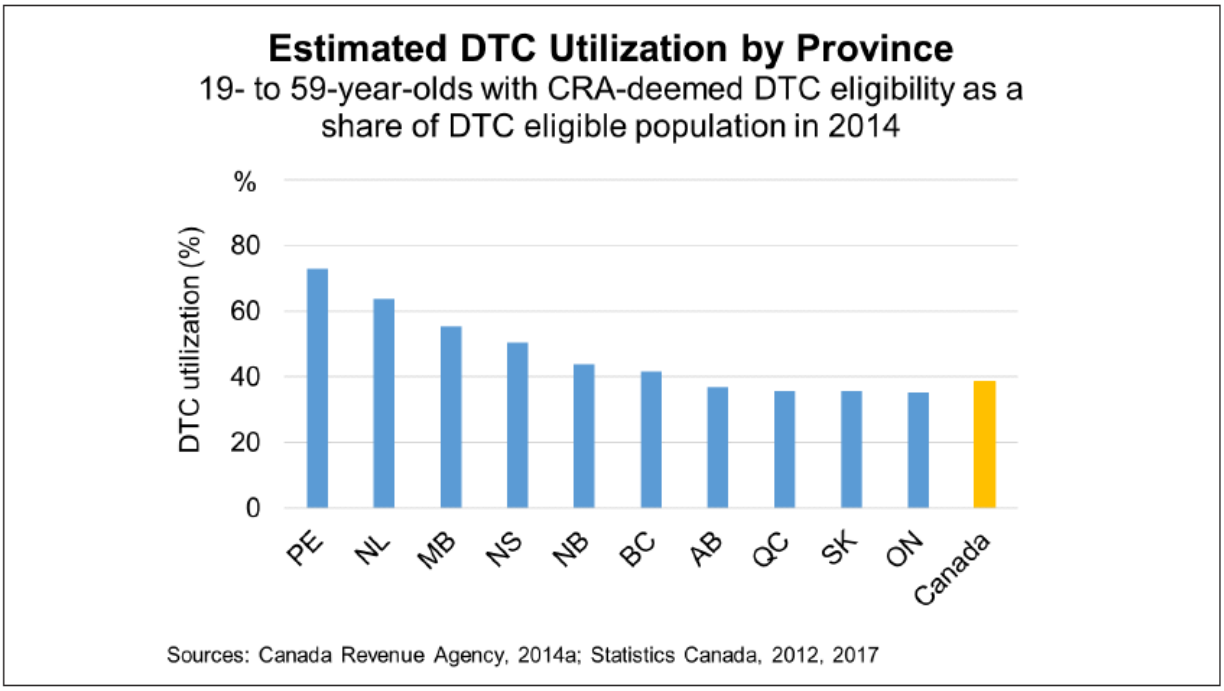
and health-related tax benefits such as the Medical Expenses Tax Credit, as part of a broader tax reform initiative in the late 1980s.

The non-refundable tax credit design aims to promote horizontal equity by recognizing that the higher costs faced by people with disabilities are not true economic consumption and should be deducted from the income tax base (Smart and Stabile, 2006). This means that the DTC is not a subsidy for individuals with disabilities (like social assistance, for example); rather, it is a tax fairness measure that recognizes that disability costs are unavoidable additional expenses not faced by other taxpayers (Tjorman et al., 2004).

However, only an estimated 40 percent of working-aged adult individuals with a severe disability in Canada are deemed by the CRA to be eligible for the DTC (Figure 1). Inconsistencies in application reviews by CRA staff who may not be qualified to do so lay a foundation for bleak financial outcomes for this vulnerable population.

FIGURE 1



Take-up of the DTC is low in Canada but varies noticeably across provinces. Only one in three individuals with qualifying disabilities is estimated to have CRA-deemed eligibility to the DTC in Alberta, Ontario, Quebec and Saskatchewan.

The Disability Tax Credit is the gateway to sheltered tax savings

Qualifying for the DTC – which is not automatic – provides access to a number of other federal and provincial benefits, such as the Child Disability Benefit and provincial DTC supplements. DTC eligibility also enables individuals to establish a RDSP and qualify for up to $20,000 and $70,000 in government

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bonds and grants, respectively, over the lifetime of the plan and up until they turn 50 years of age, depending on contributions and family income (outlined in more detail in Table 1).[1]

The implications of DTC eligibility are significant, particularly for families with children with disabilities and to a lesser extent for lower-income adults with disabilities.

TABLE 1 DISABILITY SUPPORTS REQUIRING DTC ELIGIBILITY IN 2017

	Family with a child with a severe & prolonged disability under 18 years of age	Adult with a severe & prolonged disability
DTC eligibility required for access	Disability Tax Credit (federal and provincial)[1] DTC Child Supplement (federal and provincial)[1] Child Disability Benefit Home Accessibility Credit Home Buyers' Plan Registered Disability Savings Plan Qualified Disability Trust	Disability Tax Credit (federal and provincial)[1] Home Accessibility Credit Disability-related Employment Benefits Registered Disability Savings Plan Home Buyers' Plan Qualified Disability Trust
DTC eligibility provides additional benefits	Medical Expenses Tax Credit Child Care Expenses Deduction Tuition, Education and Textbook Amount Home Buyers' Amount Registered Education Savings Plan	Medical Expenses Tax Credit Working Income Tax Benefit Tuition, Education and Textbook Amount Home Buyers' Amount Registered Education Savings Plan

[1] For all provinces except Quebec

KEY ISSUES AND RECOMMENDATIONS

1. CLEAR, TRANSPARENT AND INFORMED APPLICATION, REVIEW AND APPEALS PROCESSES

The DTC application form (T2201 Disability Tax Credit Certificate) and application and review processes are not applicant-friendly, according to submissions to the CRA's public consultations in 2014 (Canada Revenue Agency, 2014). This finding is also supported by the proliferation of third-party companies offering to help people, for a fee, to apply for the DTC. This industry's activities necessitated the creation of legislation limiting the fees applicants may be charged for the service, although the CRA has yet to implement regulations for these fees.[2] Members of Parliament have also noted that budget cuts to the CRA in recent years have reduced access to help and information, and this is consistent with recent Auditor General of Canada findings showing that two in three calls to the CRA's call centres are unanswered ("Bill C-462 (Historical). Disability Tax Credit Promoters Restrictions Act. House Debate,"

[1] The RDSP is jointly administered by Employment and Social Development Canada (which governs the administration of the grant and bond, outreach and awareness, and reporting on program expenditures) and the CRA (which provides the legislative framework for the RDSPs and administers the DTC).

[2] In 2014, Bill C-462, the *DTC Promoter's Restrictions Act*, was introduced to limit the amount that third-party companies could charge to help people with disabilities lodge DTC applications. A submission from the Canadian Medical Association to the government noted that it was "concerned that one of the reasons individuals may be engaging the services of third-party companies is a lack of awareness of the purpose and benefits of the Disability Tax Credit. Additional efforts are required to ensure that the Disability Tax Credit form be more informative and user-friendly for patients." ("Bill C-462 (Historical). *Disability Tax Credit Promoters Restrictions Act*. House Debate," 2013).

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2013; Office of the Auditor General of Canada, 2017). This creates an even greater barrier to accessing the DTC for those with fewer resources to seek paid professional advice.

As background, an applicant is required to find (and pay) a physician or a specified allied health professional to complete their application form. This certifies that they are markedly restricted in performing a basic activity of daily living all or substantially all of the time, or that the cumulative effect of restrictions across several activities is equal to being markedly restricted in one basic activity of daily living. The basic activities of daily living include: walking, vision, hearing, speaking, dressing, feeding, eliminating and mental functions for everyday life.

Examples of barriers in the application process include:

- **Finding a health professional aware of the DTC and willing to complete the application form**. This is especially true for autistic adults who are no longer under the care of a pediatrician. Some professionals refuse to complete the form, particularly for patients with mental illnesses, because they do not know the patient's full history, or owing to the poorly defined criteria and legal risks of making false statements (Goffin, 2017; Ross, 2016).

- **Cost versus (perceived) benefit.** The non-refundable design of the DTC may discourage lower-income earners from applying because the high application costs are outweighed by the perceived low benefit of the credit itself.

  The amount of the federal credit multiplied by the lowest tax rate yields a non-refundable amount. In the 2016 tax year, the calculation would have been: $8,001 x 15 per cent, or $1,200 if the applicant had sufficient taxable income and nothing if the applicant had no taxable income. A recent study showed that around half of DTC claimants received little or no value from the credit itself because their taxable income was too low (Simpson and Stevens, 2016). Yet as outlined above, eligibility for the DTC provides additional benefits beyond simply the value of the credit itself.

- **Health professionals may struggle to describe how the applicant's disability impacts activities of daily living.** This has led to recommendations for the CRA to formally recognize supporting information from family members and other people familiar with the applicant (Canada Revenue Agency, 2015).

- **Requirements to re-apply for the DTC create additional burden on individuals with severe and lifelong impairments in mental and physical functions.** Some individuals, including all children, are only granted temporary eligibility and required to re-apply at a later date, even those with severe lifelong disabilities. This has prompted calls for a simplified renewal process (Canada Revenue Agency, 2015).

- **Confusing follow-up requests from the CRA to medical practitioners for additional information may see some individuals wrongly denied eligibility.** For example, this issue was raised in a

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recent appeals case, which found that the CRA's follow-up request for information to the health professional completing the application was unclear and not a legal test for eligibility ("McDermid vs. The Queen, 2014 TCC 264 (CanLII)," 2014).

- **Lack of consistency and transparency in CRA processes**. This includes concerns about inconsistencies in how applications are reviewed, whether those reviewing applications are qualified to do so, opaque internal review, reconsideration and appeals processes, and the withholding of documentary evidence by the CRA during appeals processes (Weissman & Buchanan, 2016).

Recommendations for action include:

- **Introduce a clear and transparent review process for the DTC**. This involves ensuring appropriately trained staff are assessing DTC application forms and internal eligibility decisions are made in a reliable and consistent manner.

- **Introduce a clear and transparent appeals process for the DTC.** A clear and transparent appeals process needs to be established for those denied eligibility. There should be support for the applicant and the physicians or professionals who complete the forms to gain clarification and better understanding of how to appropriately navigate the appeal process effectively.

- **Remove the requirement to re-apply for the DTC in the presence of a lifelong disability.** Allowing exemptions for those with conditions known to be lifelong removes the burden of regular re-application. This saves time and cost for the applicant and is time saving for the professionals who complete the forms.

2. CLEAR, CONSISTENT AND UNIVERSALLY ACCEPTED CLASSIFICATION CRITERIA FOR DISABILITY

The T2201 form and eligibility criteria were originally designed to address individuals with physical disabilities. They are inadequate, inappropriate and ineffective in assessing the eligibility of those with autism as they do not accurately assess whether a person has a severe and prolonged impairment that impacts their basic activities of daily living. Examples include:

- **Administrative interpretation of eligibility criteria that do not have statutory basis.** The CRA's position that being "markedly restricted" is defined as an impairment in function being present "at least 90% of the time" is an administrative position not reflected in the Income Tax Act. This remains on the application form to this day even though a body of case law has recognized this is not an appropriate measure of the effects of an impairment ("Watts vs. The Queen, 2004 TCC 535 (CanLII)," 2004). A similar criticism has been raised about the CRA's use of the phrase "life sustaining" in relation to therapy. As a result of administrative interpretation, some individuals may be denied eligibility.

- **A lack of clarity in eligibility criteria.** This results in criteria being interpreted inconsistently by health professionals completing the form, and may see some individuals wrongly denied

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eligibility (Goffin, 2017; "Mullings vs. The Queen, 2017 TCC 133 (CanLII)," 2017; Ross, 2016). For example, the current eligibility criteria require health professionals to determine whether a patient is markedly restricted in one basic activity of daily living because of their impairment "all or substantially all of the time (at least 90% of the time)", or whether the cumulative effects of a patient's multiple impairments are equivalent to being markedly restricted in one basic activity of daily living. These criteria can be confusing to interpret, with little additional clarity provided by the CRA's definition of "all or substantially all of the time" as being "at least 90% of the time". These criteria are also not aligned with current International Classification of Function criteria (the international standard to describe and measure health and disability).

Recommendations for action include:

- **Implementation of universally accepted classification criteria.** In order to eliminate differentiation based on 'mental' or 'physical' health conditions, the CRA must utilize internationally recognized criteria such as the World Health Organization's International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001). The ICF looks beyond a purely medical or biological conceptualization of dysfunction and takes the impact of the environment and other contextual factors on the functioning of an individual into account. The model incorporates multi-dimensional concepts relating to body function, activities, **participation** and environmental factors. Consistent and equitable evaluation is the foundation to horizontal equity and eliminating the need to stigmatize someone's level of ability.

  Statistics Canada already utilizes ICF in the Canadian Survey on Disability. Aligning criteria models will also improve the opportunity to assess utilization of benefits and gather much needed data.

3. UNCOUPLING THE RDSP FROM THE DTC

The only way to access the Registered Disability Savings Plan is to first qualify for the DTC. Sadly, the RDSP is by far the most inaccessible registered savings product supported by the federal government. This is most unfortunate given whom the product is meant to serve – those least able to secure their financial futures.

Given the severe social disability that autism entails, people on the spectrum very often struggle to find and keep jobs. They are chronically unemployed or simply rotate through a series of low-paying part-time jobs (Zwicker, Zaresani and Emery, 2017). Thus, they often do not receive pensions from employers, do not qualify for the Canada Pension Plan (CPP) and do not have sufficient income to invest in Registered Retirement Savings Plan or other savings vehicles. The RDSP is intended to provide an important buffer against chronic poverty. It would enable parents and autistic adults to plan their financial security and thereby remove prolonged financial dependence on parents and other relatives. Additionally, the financial independence provided by an RDSP would help alleviate some of the burden on the employment insurance program.

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Recommendations for action include:

- **A new assessment process for disability benefits and uncoupling eligibility for other important benefits from the DTC must be considered.** By design, the DTC is not a universal benefit – it is a tax-fairness measure that benefits those who pay taxes. Using eligibility to a benefit that does not provide value to all individuals with qualifying disabilities as a gateway to benefits with other policy objectives is poor design. This could be resolved by separating the eligibility determination for an RDSP from the DTC.

- **Additional eligibility gates to the RDSP beyond the DTC.** Consider accepting provincial income support disability designations on the same basis as the DTC as gateways to the RDSP, so that people with disabilities are not required to unnecessarily and repeatedly prove the extent of their disability.

- **Do not collapse the RDSPs of people who lose their eligibility for the DTC.** Should a person be deemed no longer eligible for the DTC they should still be able to access the federal government benefits (bonds and grants) provided to them for the time they had a disability.

- **Reinstatement of the bonds and grants upon DTC requalification.** Reinstate the RDSP, including the federal government bonds and grants, for people who requalify for the DTC, or who have let their qualifications lapse.

4. FEDERAL MONITORING AND EVALUATION OF POPULATION-BASED DISABILITY DATA

According to UNICEF, "The true measure of a nation's standing is how well it attends to its children, including their health, safety, material security, education and socialization and their sense of being loved, valued and included in the families and societies into which they are born."

As many as 850,000 children in Canada are estimated to be living with a brain-based developmental disability. However, existing national population data is out of date, with the most recent data on Canadian children with disabilities almost a decade old. Three of the four population-based disability surveys for children are no longer active, meaning we lack critical information on the often unmet needs of this group, as well as the out-of-pocket costs paid for by families. In this dearth of information, how can we design effective policies and programs that improve the social, health, employment and economic outcomes for children with disability and their caregivers?

Monitoring and evaluation of any program require accurate data to determine whether the program is meeting its stated goals. The lack of linked disability population data and benefit utilization data make it difficult for anyone – including the federal government – to assess how effective the DTC is in reaching its target population and where efforts should be taken to improve awareness and access. This is particularly important given the DTC's role as a prerequisite to other benefits (with more of a social policy objective).

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The absence of any timely national data for children with disabilities is also a concern. We currently cannot evaluate the impact of disability benefits like the DTC or the Child Disability Benefit for children with disabilities, including those on eligible therapies.

Recommendations for action include:

- **Collect feedback from applicants and professionals who complete the forms.** In order to accurately determine the effectiveness and relevance of applications, reviews and appeals processes, it is essential to gather data from those who are impacted by them.

- **Collect disability population and benefit utilization data.** Determining whether the program is meeting its goals and establishing benchmarks data is paramount to ensuring that all Canadians are treated equitably. Federal investment in national longitudinal data on children and youth with disabilities is needed (Canadian Survey on Disability only starts with age 15). With needs identified, they can be addressed.

5. INCLUSION OF THE NEURODEVELOPMENTAL COMMUNITY ON THE DISABILITY ADVISORY COMMITTEE

The recent announcement of the reinstatement of the Disability Advisory Committee (DAC) in 2018 is a promising step towards improving access to the DTC. The DAC's mandate is to review the existing administrative practices and provide advice to the CRA on improving awareness, utilization and the CRA's administration and interpretation of laws and programs relating to disability tax measures (Canada Revenue Agency, 2017). We hope the DAC will address the barriers outlined and suggest some specific recommendations to this effect. However, the complex nature of autism necessitates representation on the DAC to ensure adequate information is relayed, that all circumstances are considered and that equality is attained across all sectors of the autism population.

According the CRA (Canada Revenue Agency, 2018) in 2017 DTC applications for those falling under the category of "mental" disability were 107% more likely to be rejected when compared to <u>all</u> other application types. This is a deeply concerning pattern that is being repeated year after year. People on the autism spectrum are a vulnerable population deserving of federal supports. The autistic community is not asking for special assistance or handouts, but simply to have equal access to the federal tax credits they are entitled to.

Recommendations for action include:

- **Inclusion of a neurodevelopment health professional on the DAC**. Consider the value of input from an allied health or medical professional with neurodevelopmental clinical experience with regard to informing the establishment of criteria suitable for evaluation for a neurodevelopmental disability such as autism.

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APPENDIX

January 29, 2018: Statement on Disability Tax Credit

We, the undersigned groups, are writing to share our collective concern that a number of families of children with autism spectrum disorder (ASD) and related developmental disabilities have had their Disability Tax Credit (DTC) applications rejected by the Canada Revenue Agency (CRA). These include applications specifically for children diagnosed with Level 3 ASD, a level that indicates a child who requires very substantial support. We are frequently noting that the CRA is concluding that the impairments in children with autism are a reflection of their younger age (and cannot be adequately assessed). Autism is a lifelong neurodevelopmental disorder based on exhibited impairment.

Rejections to families place an undue burden on them in ensuring support for services and resources given the needs of children with ASD, along with an economic cost on unrealized potential. It detracts from the original purpose of the DTC. It also impacts the ability of physicians to deliver care at the same time as needing to fill out additional paperwork that is often redundant. More specifically, physicians are spending hours per week filling out the original applications, filling out requests for further information, and writing letters of support for families who are appealing the rejection. There is a lack of clarity in what is expected from the CRA in terms of information required, and many physicians continue to re-iterate the evidence already provided in the original application. The process is resource-intensive for physicians and highly stressful for families, and negatively affects the mental and emotional well-being of families, ultimately leading to more spending on healthcare.

There is an urgent need to making the application more explicit in what the CRA is looking for with regards to eligibility criteria and providing feedback to physicians about what the CRA is not currently approving based on the current categories. This lack of transparency in the decision-making process is contributing to inefficient use of physician resources and a lack of ability to advise families on eligibility for the DTC. We would be very willing to discuss our experience in more detail, and can be reached at m.s.zubairi@gmail.com.

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