



February 19th, 2020

Dear Disability Advisory Committee members,

Re: DTC eligibility issues related to autism

CASDA would like to thank you for your work on understanding and addressing the issues faced by people in accessing the DTC, and the specific attention paid in their first annual report to the particular challenges faced by those with Autism Spectrum Disorder (ASD).

As the committee has highlighted, the DTC assessment process does a poor job of accounting for disabilities related to intellectual or mental function. The existing tests lead to people with ASD being rejected at a much higher rate than those with physical disabilities, and being treated very inconsistently across Canada and over time. The unwarranted variation across individuals and even, the year-by-year changes, for people with ASD is concerning.

First and foremost, the form was originally created for people with physical disabilities, and not people with mental health or neurodevelopmental conditions. Required supports and the intensity that is offered comes in many forms, and it is important for the DTC to consider the variability in the support needed for individuals with autism spectrum disorder. Here are some more specific comments:

- We have received reports from parents that the CRA told them their child was too young to be diagnosed with autism -- even though a medical professional had already made an autism diagnosis. Autism can be diagnosed very early, especially when an older sibling has received a prior diagnosis. Others were told that their autism is not enough of a disability for them to be able to complete life tasks.
- The other issue is that medical doctors are the only professionals that are permitted to fill out all sections of the forms. Psychologists can only complete the section on mental disorders. In some instances, psychologists often are the health care professionals who have both diagnosed the individual and have supervised their intervention programs, hence, know them best. For example, if the child also has severe motor delays and severe language disorder (as part of a multidisciplinary assessment), that should be mentioned but they cannot report those results due to the section restricted to their profession.
- Another repeated problem we hear from our members is that parents have to obtain the services of a healthcare professional to fill out the form once they are flagged for a "revision", and they don't always have such a person after their initial diagnosis. For the initial application, parents can request the diagnosing physician or psychologist to complete the form, but unlike some other chronic childhood conditions, children with ASD are not often followed closely by medical professionals after their diagnosis. Many of these families do not have a pediatrician or family doctor that they see over time due to shortages in family doctors, for example. Some of our families therefore rely on doctors that they see in walk-in clinics to fill out these tax forms for them when they need to reapply after the initial diagnosis. This is obviously problematic since those doctors do not really know the children and are lacking the information they need to be able to complete the form and to speak to the child's need for support.
- Very few services are available for people with an ASD in the public system and parents will often pay for services out of pocket and often stop working to care for these children,



and this is a very small amount that serves to recognise the financial impact of caregiver time.

- Increasing the flexibility of around which professions can fill out the form could be beneficial. Specifically, we believe would be worth exploring the possibility of having other professionals able to fill in the form for re-applications, such as Board Certified Behaviour Analysts, who provide services for people with an ASD (especially for early learners) as included as professionals who can attest for the person's functioning.
- Psychologists who have knowledge of ASD, feel that the forms are too focused on the results on IQ and Adaptive behaviour testing, as opposed to considering that autism is a lifelong neurodevelopmental condition, that is also known to have very strong comorbid conditions: including speech, language and communication disorders, mental health issues (including anxiety disorders, behavioural difficulties, ADHD, and depression), as well as a higher proportion of sexual and gender diversity. These aspects of a person's functioning, together with the "primary" ASD diagnosis are what affect functioning and the need for support for an individual.
- Although there is a space in which to answer questions on SPEAKING, there is no appropriate section for Communication. That is, what are the support needs to help the person communicate with others (ex. The use of augmentative and alternative modes of communication, if a person has severe deficits in the use of social communication, this could also be noted in this section).
- There are sections on Feeding and Dressing, however, it would be of great help if these forms could focus on Executive functioning and planning. Many individuals with ASD, both old and young, seek support for Executive functioning and planning, and their autonomy suffers greatly in these domains. Examples include awareness of danger, bolting, extreme naiveté or gullibility, etc.

The cumulative effects of these associated conditions explains their accrued need for support. Overall, a clear and consistent classification criterion is needed. And this should be outlined in a transparent, evidence-based application review process. The current eligibility criteria require health professionals to determine whether an individual 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. Recommendations for using universally accepted classification criteria such as the World Health Organization's International Classification of Functioning, Disability and Health (ICF). 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.

CASDA is happy to bring experts together to support changes in this direction if needed. Because the DTC is a gateway to accessing other benefits and programs (like RDSPs), this inconsistency and uncertainty can wreak havoc with family finances and well-being.

Second, the process is also unnecessarily cumbersome, taxing people with disabilities, their families, and healthcare providers that they work with. This takes time and attention away from care and support.

- Since ASD is a lifelong neurodevelopmental condition, it is not relevant to reassess the person's functioning, as symptom presentation and comorbid conditions will change over



time. It is, in our clinical opinion, unnecessary and very costly for families to be reassessed. The wait-times to see a specialist in the public sector is over 2 years, and for specialists working in the private sector, costs often surpass a thousand dollars for a reassessment. Therefore, the DURATION section, where a person is asked whether their condition will improve is difficult for clinicians to answer. There may be improvements in comorbid conditions or language, for example, but a person will always be autistic. We have members reporting families that with severe and profound impairments having to re-apply for the credit frequently. Making families continue to prove that their children are still significantly delayed is heartbreaking for families.

- Further, many families reported they often had to wait months or close to a year to find out whether they or their child qualified, and often had trouble accessing information about their application through calls to CRA call centres.
- From a first-person perspective, adults on the spectrum are also reporting that they are responsible for renewing their DTC application. Often denied at first, the adults who rely on this credit can lose their qualifications for the RDSP as well as financial help during this time. Some in our community have called for the uncoupling of the RDSP from the DTC to mitigate these risks.

Third, the government has committed to a National Autism Strategy - something that we at CASDA have been advocating for many years. As part of that strategy we see an opportunity to improve the following:

- Recommendation to create a new form that would reflect the required supports for people with neurodevelopmental conditions
- Recommendation to have a separate form for children and adults
- Recommendation to have a more flexible definition of mental function impairment, specifically, a recommendation to include Communication domains as well as Executive functioning and domains that would capture mental health aspects that are comorbid to living with an ASD.
- Recommendation to use the WHO's ICF framework for eligibility. Transparent, clear criteria would allow eligibility to be more based on need than the ability of the professional using the right words to fill out the form.
- Recommendation to permit psychologist to fill out all sections of the DTC. Often, it is psychologist who can cumulate the information from other professionals.
- Recommendation that for children, Board certified behaviour analysts can also fill out the forms.
- Recommendation that Autism Spectrum Disorder be recognised as a lifelong neurodevelopmental condition
- Recommendation that for Autism Spectrum Disorder, it is not relevant to reassess the person's functioning, as symptom presentation and comorbid conditions will change over time.

We would encourage the DAC to engage with the ASD community, including self-advocates, on the specific issues that people face. CASDA is happy to facilitate these consultations as you need. We would be happy to suggest subject matter experts as needed.



Appended to this letter is a recent, first-person account of the CASDA self-advocate member and leader. I hope that this will be informative in illustrating the barriers that can be addressed by this committee.

Once again, thank you for your time on this matter. Please feel free to contact us if you have any other questions or concerns.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Jonathan Lai', is written over a light blue horizontal line.

Jonathan Lai

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Appended – first-person account of a CASDA self-advocate member and leader’s experience with the DTC

My DTC renewal last year was denied and the appeal was denied. The second appeal was accepted, but it was I believe over a year of it all being not operational. During that time, my RDSP was cancelled and everything. I went to CBC and researched others who had experienced these things.

Here's my full story:

Recently my Disability Tax Credit renewal expired, and I was not aware that it had (ie: I received no documents in the mail letting me know this was going to occur). I finally became aware on my own volition when I discovered that the government was no longer matching my RDSP contributions.

I then contacted and found out from the CRA I would need to reapply for the Disability Tax Credit. It had already been several months that my status had been expired, and there were several pages of confusing and complicated paperwork to complete the renewal, it took me a long time to reapply.

After I completed the renewal package I waited for it to be assessed beyond what I was told was the appropriate waiting period (12+ weeks) so I called the CRA to inquire about my claim status, and got no answers. They did not have an idea of when my application was received or when it would be assessed, or anything because they did not know those things until the application was in a state of 'done'.

I can't remember if I then had to completely reapply, or if I just had to wait another 8-12 weeks before I received a letter in the mail saying that some additional paperwork had been sent to my physician asking him for more information pertaining to my condition. Although I am not ruling out that I didn't have to completely reapply.

After this letter, and several more weeks, I received a Notice of Determination letter saying that my application for DTC would not be approved and the letter contained a lot of circular and vague language, that I had to read several times to discover didn't really give me many answers.

For example there were phone numbers to call on the letter, for more information regarding my case, however it was (with written language) unclear which one I could call and for which reason. So literally vague language was being used on purpose in most every written communication from the government to people with disabilities. I ended up having to call both, and only one gave me much insight into my renewal case, and neither was very helpful in the end (as I am several more months down the road with still expired status and an actual time limit on how long I can be in this status before my RDSP is permanently revoked).

I then came to realize that the 9 months of contributions I had been making into my RDSP fund (the time which CRA had been 'processing' my renewal) I was invalidly contributing into my 'expired' fund.

From what I understand from a June 2018 CBC News article, it is possible that the grants and bonds that the government has made during the time I was eligible for RDSP might all be for nothing if my appeal is not successful.



This is alarming, because my disability status hasn't changed. And, as it appears to be, thousands of others are also affected - not only by the DTC renewal process changing, but by the RDSP invalid contributions being made in error by the banking institutions. I mean that RBC did not stop my automatic contributions to the plan when the CRA sent RBC messages saying that the RDSP was frozen until the DTC was renewed.

The Disability Tax Credit cut occurs for many people during their renewal process and without any written prior notice. Many of these Canadians are autistic, and bipolar - affecting their ability to handle paperwork such as the lengthy appeals process CRA requires in the case of denial of their claims.

[The bank] has told me that they will not credit me back for the contributions that I put into the RDSP while it was frozen, even though the bank received a notice from the CRA each time I made an invalid contribution unknowingly to myself.

The CRA did not tell me that my DTC had become in state where I would need to renew it, nor did they let me know that this affected my RDSP. I continued to invest my money improperly without knowing that I was doing this, and now I am told that no one will correct this.

I am told by [the bank] that they can do 'nothing for me' in regards to the 900\$ of contributions that I made into my RDSP during the time in which it was a frozen account, and in which time each contribution was flagged by The Canada Revenue Agency to [the bank] as an invalid contribution. For example, even if I were to appeal my being denied DTC, and my RDSP reinstated, the contributions I had made during the time I 'was not eligible for RDSP' would not be honoured by the program.

My second appeal with CRA, which required my doctor to fill out additional information and really press the issue of my incapacitation under the criterium and necessity for status to remain active - actually did become enough to grant my renewal of DTC. Which was a huge relief, but when actually looking at the situation, is an enormous pain in the behind because I lost the RDSP contributions from the government for 900\$ of my own, and it was a lot of stress and paperwork spanned over I think a year or so - most of which was way beyond confusing and unnecessary, considering the nature of my disability had not changed one iota.

One of the major things that bothered me is that major banking institutions are aware that consumers are making RDSP contributions into their investment accounts, while their accounts are deactivated, and the consumer is unaware that it is deactivated. I mean that, the client does not know that their DTC has expired and their RDSP along with it. Mostly this is happening because CRA is not telling the clients that DTC is about to or has expired, and secondly that the renewal process is flawed in a lot of ways leading people to get denied their renewals, and thirdly, a LOT of the communication language through this whole process is too vague and generic or the wording too confusing or complicated for the clients to be successful in processing their renewals themselves.