



July 27, 2019

Important Update Regarding Our Campaign for Extended Health Benefits

We would first like to thank all supporters of our campaign for justice in Extended Health Benefits in the Northwest Territories. This campaign was launched on June 13, 2019 and in the past week and a half we have reached thousands of NWT residents through radio, television, online articles, and social media. We have also had incredible support from many residents who have taken the time to reach out to their elected officials to amplify our message and demand change by: (1) removing discrimination enacted in policy for the Extended Health Benefits for Specified Disease Conditions Program; and (2) address a critical gap in the provision of supplementary health insurance that provides no benefits for low-income residents. This update is to provide new information about our engagement with the Department of Health and Social Services and to let our supporters know the strategy of our campaign moving forward as we continue to advocate for these important changes.

On June 13, 2019, we presented our position paper to the Minister of Health and Social Services. This report was focussed on two substantive issues: (1) that a list-based eligibility system is, by definition, in violation of the Canadian Charter of Rights and Freedoms; and (2) that the NWT has no formal supplementary insurance program for low-income residents. Our stance was clear and articulated in our calls for reform that, firstly, requested that immediate action be taken to remove discrimination from the Extended Health Benefits for Specified Disease Conditions Program by determining eligibility on the basis of medical need and not specific diagnosis; and, secondly, requesting that the Department of Health and Social Services take action to address the unmet health needs of low income residents who lack supplementary health insurance. In our campaign, we released this position paper along with a public email-writing campaign. In this campaign, we highlighted Autism as one condition that was ineligible for coverage as it was not one of the 50 conditions listed by the Extended Health Benefits for Specified Disease Conditions Program. The fact that Autism was not covered was verified through months of research and direct conversation with officials from the Department of Health and Social Services who informed us that, because Autism was not on this list, individuals with the diagnosis were not eligible for coverage under the program. To be clear, our organization used Autism as a specific example of how this discrimination was enacted, but our core messaging was not simply to add Autism to a list for coverage; rather, it was—and still is—to demand that a system that ties eligibility to a list of diagnoses, thus violating the Charter, is removed for a neutral assessment of medical need and, additionally, that the supplementary insurance needs of low-income residents be addressed.

On June 20, 2019 we received an official response to our campaign from the Minister of Health and Social Services. In this communication, we were presented with new information that, surprisingly, informed us that Autism actually is eligible for coverage through the Extended Health Benefits Program under the diagnosis "Chronic Psychosis". Additionally, we were informed, for the first time, that some of the conditions included on the list by the Extended Health Benefits for Specified Disease Conditions Program actually serve as 'categories' that include sub-diagnoses, as per the International Classification of Diseases. This information was surprising to us because neither the Department of Health and Social Services website, the official governing policy (Policy 49.07) of the program, nor the Department of Health and Social Services' own officials, have ever identified to us that Autism was eligible for coverage or that some conditions on this list were categories, rather than specific diagnoses. We know for a fact that, up until this point, numerous individuals and families have been advised by the Department of Health and Social Services not to apply to the Extended Health Benefits for Specified Disease Conditions Program because their condition was not specifically listed. We are also aware of multiple cases of



individuals with Autism not applying to the program because their disability was not on the list and, because of this, they understood themselves to be ineligible. That being said, we welcome this new information, which, up until this point, has been inaccessible to the public. We have expressed our concern to the Department of Health and Social Services about this clear inaccessibility of information and have formally requested that they provide us with a complete list of exactly which conditions constitute a 'category' and a full list of all eligible sub-diagnoses. We have yet to receive this; however, we will share this widely once it is received. We have also encouraged the Department of Health and Social Services to take responsive action and clearly indicate on its own website and application form that some of the 50 listed diagnoses are, in fact, categories and provide a list of the conditions that each category includes. This is straightforward corrective action that we hope is taken. We especially hope to see this action taken considering that after being in contact with the Extended Health Benefits Program through the Department of Health and Social Services on June 26th, we were, once again, told that Autism was ineligible for coverage and it was not until multiple phone calls were exchanged that consensus amongst individuals who actually administer the program was reached that Autism actually was eligible. At this time, we were also informed that information about diagnoses that were actually 'categories' was just given to the program administrators and to physicians in the NWT within the past 24 hours of us contacting them. We were also directed to contact Senior Management about any further questions about Autism being covered because front-line and mid-level management were still unaware of this new information.

That being said, the fact that this new information indicates that Autism and select other diagnoses are also included for coverage under the Extended Health Benefits Program changes nothing about the substantive legal argument against the use of a delineated list of conditions as an eligibility requirement for accessing coverage. Additionally, this new information changes nothing about the lack of supplementary insurance benefits available to low-income residents. These were the two areas of reform we actually requested. We never made a request for Autism to simply be added to a list. As an organization, we were using Autism as an example of an ineligible condition for coverage, which based on the available information, was our understanding at the time. The position paper released mentioned nothing of Autism specifically and, rather, outlined a broader legal argument against the use of a specific list of conditions as an eligibility requirement and supported this with Charter case law. Additionally, the paper highlighted a significant gap in the delivery of supplementary insurance for low-income residents. Finding out that the list for coverage was longer than we had thought changes nothing about the central tenants of our campaign. We will continue to support this campaign as well as the efforts of other NGOs who we welcome to join us in a leadership capacity. Even with the additions to the Extended Health Benefits for Specified Disease Conditions Program, there are still numerous diagnoses that remain ineligible for coverage, including, for example, intellectual disabilities, anxiety disorders, and ALS. Furthermore, it remains true that 37 formal requests for new conditions and 155 denied applicants from 2015-2017 have not led to any meaningful change in this program.

In releasing this new information that Autism is actually covered under the Extended Health Benefits for Specified Disease Conditions Program, the Department of Health and Social Services has addressed neither of our actual substantive arguments. We will continue to advocate for the removal of discrimination from health policy and equitable access to supplementary health insurance for all. It is our core belief that access to insurance should not be dependent on a person's diagnosis or their income. We know this is a belief that many people in the NWT also share. Continued public engagement with elected officials will only strengthen our work and we strongly encourage supporters continue their efforts.