Canadian Psoriasis Network
Réseau canadien du psoriasis

CAPP ACPP
Canadian Association of Psoriasis Patients
Association canadienne des patients atteints de psoriasis

September 27, 2021

Re: Disability Inclusion Action Plan consultation

To Whom it May Concern,

On behalf of the Canadian Psoriasis Network and the Canadian Association of Psoriasis Patients, we are writing to provide our feedback on the Disability Inclusion Action Plan. We have reviewed the survey questions and provided our perspectives on the four pillars: financial security, employment, disability inclusive spaces, and a modern approach to disability.

Psoriasis affects up to 1 million Canadians and is a chronic inflammatory condition of the skin, causing itchiness and pain. Approximately 30% of people with psoriasis live with psoriatic arthritis (PsA), a chronic, autoimmune form of arthritis that causes joint inflammation, pain, and stiffness in the joints. Often people with psoriasis or psoriatic arthritis are in their prime working years. Psoriasis symptoms can begin at any age but often begins between the ages of 15 and 25. People with psoriasis or PsA often live with comorbidities, including diabetes, depression, anxiety, and cardiovascular disease, causing further stigma and discrimination. These health conditions are episodic in nature – meaning people can experience periods of low disease activity followed by a flare or exacerbation of disease. Because these illnesses are lifelong and affect financial security, employment, and transitions from school to work, it is important that early support and take action to support people living with psoriasis and PsA.

We recently conducted a survey to better understand the workplace needs of people living with psoriasis and PsA. Close to 200 people responded and approximately 70% of survey participants had been working for more than 10 years while living with psoriasis or PsA. They are affected by social stigma associated with visible signs of psoriasis and poor understanding of invisible signs of the condition(s), such as pain, depression, and anxiety. Over 85% of participants indicated that they worry about psoriasis or PsA.

## *Financial security*

Financial security is the most critical pillar to address in the creation of the Disability Inclusion Action Plan. People living with psoriasis or PsA experience ongoing threats to their financial security due to difficulties in labour market participation and medication costs. The COVID-19 pandemic has also worsened financial security for some people living with psoriasis or PsA. One quarter (27%) of participants noted they worried about their finances and one third (35%) indicated that they were worried about keeping their job or business operating during the pandemic. Many vulnerable groups, such as people with disabilities, experienced disparities throughout the pandemic including higher rates of infection, increased impact of isolation measures and experienced job loss or reduced hours and decreases in household income.

Many social programs, such as the CPP-Disability (CPP-D) benefits and provincial disability support programs assume a disability to be permanent. Further, any improvement in a disabled person's financial situation means benefits are clawed back or subject to review by government staff. Greater flexibility is needed in these programs to represent the episodic nature of disability meaning people should be able to work and receive support during periods where they are temporarily unable to work.

There are also different approaches to achieving financial security, such as adapting current programs to the needs of people with disabilities (e.g., Canada Child Benefit) or providing a basic income.  These programs must provide the same flexibility to address episodic disability while also providing freedom to people to make their own decisions, without fear of claw backs by the government. The respect and dignity of people with disabilities and ability to control their situation and future are integral to any policy change or adaptations. Often existing programs are difficult to access due to restrictive eligibility criteria (e.g., Disability Tax Credit) and might only benefit a small subset of people with disabilities. The monetary support provided through these programs is not sufficient for many people with disabilities and surpassed what is provided to workers affected by the COVID-19 pandemic through the Canada Emergency Response Benefit (CERB) / Canada Recovery Benefit (CRB).

The financial security of people with psoriasis and PsA are also at risk due to the cost of medications needed to treat the conditions. Medications can cost a significant amount, especially for advanced therapies such as biologics where costs can be as high as $30,000 annually. Even when enrolled in public drug programs, copayments can be prohibitive for people who do not have adequate private insurance coverage. According to our recent survey, 43% of participants were worried about changing jobs because they might lose their health care benefits.

To address these issues, labour market incentives should be introduced to support businesses who employ people with disabilities as well as businesses owned by people with disabilities. In addition, any proposed changes must be co-designed with people who receive income support program benefits and must take into consideration other crucial social programs and supports that people need (i.e., pharmacare, access to public drug programs, livable wages). Ongoing access to public drug programs will continue to be needed for people living with health conditions, such as psoriasis or PsA. A robust drug formulary should be established to ensure access to the range of medications needed to treat the disease(s). For example, even with access to a drug plan, 38% of participants indicated that the drug plan only reimbursed certain medications, causing an additional barrier to drug access and reimbursement.

### *Employment and disability inclusive spaces*

Employment and financial security are related concepts since participation in paid employment directly improves a person's financial security. Over 65% of survey participants noted that PsA had a negative impact on their work, while 50% noted the negative impact of psoriasis on their work. Common challenges included: staying focused due to itching, pain and fatigue, performing physical tasks, and reporting to work at the scheduled time.

Accessing accommodations can be challenging and only 30% of participants indicated they can access the workplace accommodations needed for their job. One third (33%) of participants said supervisors did not understand the episodic nature of disease suggesting additional barriers to accessing needed workplace accommodations. There are also physical barriers to work, such as inadequate office set up and access to workplaces. Approximately 30% of participants indicated that there are physical barriers at work, e.g., inadequate office set-up and standing for long periods.

Direct support to people with disabilities is needed to navigate workplace situations, such as advice from an independent human resources specialist, employee assistance programs, and paid sick leave. Incentives could be provided to small and medium sized organizations to enable access to some of these supports (e.g., tax incentives, reimbursement of technical aids, wage subsidies, free legal or Human Resources advice), or the creation of free supports, such as those available through ARCH disability law centre. Not for profit organizations could help address some of these gaps too with appropriate federal funding made available to them to provide these critical services.

### *A modern approach to disability*

Canada's current approach to disability continues to uphold the medical model of disability and does not recognize that society imposes many barriers to the participation of people with disabilities in life. Similarly, current government programs to support people with disabilities create barriers: while there are many programs available, many potentially eligible people are not aware they exist, or the criteria are strict (e.g., CPP-D, Disability Tax Credit) limiting who might benefit. Navigating the different programs is difficult especially for those with fewer resources or less education. Programs need to be co-designed with people with disabilities and have a single-entry point. Administrative processes should be streamlined, requiring only one application to facilitate access to all federal and provincial programs and using a definition of disability that is consistent with the social model of disability and that recognizes the nature of episodic illnesses. This recommendation, among others, is noted in the Pan-Canadian Strategy for Disability and Work. The federal government can be a model within Canada and take a leadership role in working with the provinces to achieve the goals laid out in the *Accessible Canada Act*.

In closing, we ask that you consider the ideas proposed in this letter and we ask that you work with us, with people with disabilities, and with other organizations, to design an action plan for inclusion that supports the independence, respect, and integrity of people with disabilities - including episodic disabilities. We thank you for the opportunity to provide our perspective on behalf of people in Canada living with psoriasis and psoriatic arthritis.

Sincerely,

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| Antonella Scali | Rachael Manion |
| Executive Director | Executive Director |
| Canadian Psoriasis Network | Canadian Association of Psoriasis Patients |