

A Briefing Note to Advise HUMA on the Canada Disability Benefit:

Background:

People with inflammatory arthritis experience a significant amount of disability, pain, reduced quality of life with regard to social, psychological, financial wellbeing. Arthritis is a leading cause of pain and disability in North America resulting in impairments, restrictions in activities of daily living and participation in life including work. The public perception of arthritis still is that it's not serious, "just aches and pain that everyone gets as they age". People do not understand how debilitating and disabling inflammatory arthritis is until they receive a diagnosis. Other diseases have supports in place to help them navigate their treatment but patients with inflammatory arthritis have to navigate a complex system on their own.

The Canadian Arthritis Patient Alliance is a grassroots, patient-driven and managed organization that uses the power of information, research, and communication to help people living with arthritis find their voice and support others. We would like to provide policymakers with recommendations on the Canada Disability Benefit (CDB) based on the lived experience of persons who live with arthritis and related conditions.

Issue:

Close to one million Canadians live with inflammatory arthritis, a group of systemic autoimmune diseases like Rheumatoid Arthritis, Psoriatic Arthritis, Systemic Lupus Erythematosus and Ankylosing Spondylitis. These diseases impact children to seniors and cause significant pain and disability that impact participation in work, family, parenting, and activities of daily living. People with arthritis experience a range of issues in accessing disability programs federally including the Canada Disability Plan – Disability Benefit, Disability Tax Credit, accessing and getting reimbursement for prescription medications and in staying in the workforce. These challenges also extend to provincial programs like disability income support programs and public drug programs with additional challenges in accessing health care needed to manage their health.

Considerations:

We would like to highlight a few key areas to consider as part of the design of the Canada Disability Benefit:

1. **Increase the amount of paid and volunteer work allowed for beneficiaries** – Working and volunteering is significantly impacted if one qualifies for Canada Pension Plan – Disability Benefits. Current pay and work allowed is capped at \$6,400 (before tax) in 2022 which further restricts the ability of people with disabilities to participate in social and economic life. The government of British

Columbia [allows for \\$15,000](#) to be paid annually so people with inflammatory arthritis can work and could be used as a starting point for policy changes.

2. **Recognize episodic disability** – The conventional view of disability is that it is a persistent and unchanging limitation. However, many persons with disabilities, including arthritis, may not follow this stable pattern. Instead, they may experience periods of good health interrupted by periods of their limitations (on-again/off-again episodes) or their limitations may change over time (worsening, improving, or fluctuating). Of the 6.2 million persons with disabilities aged 15 years and over, 2.4 million (39%) experienced conventional continuous limitations whereas [3.8 million \(61%\)](#) experienced some type of disability dynamic.
3. **Integration with the national pharmacare discussion** – To date, the discussions about the CDB have focused on social and income support programs. We ask that the CDB and related programs work in concert to increase the supports available to people with disabilities and do not cancel each other out. National pharmacare is at the early stages of development federally and it is important to include access and reimbursement of medications as part of the policies affecting people with disabilities, including rheumatic conditions.

Recommendations:

We recommend the following changes to the Canada Disability Benefit Act and its implementation:

- Increase the amount of paid and volunteer work allowed for beneficiaries of the Canada Disability Benefit.
- Explicitly add a definition of disability to the proposed legislation and specifically include episodic disability in this definition.
- Integrate conversations about national pharmacare into the debate and deliberation about the Canada Disability Benefit.
- Include people living with disabilities AND episodic disabilities in the development of ALL policies that impact their life.

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