Statement of Common Agenda
on Disability, Full Participation & Work

Press release
For immediate release

Canadians living with episodic disabilities call for reform to benefit programs

Ottawa, May 4, 2005 – Today on Parliament Hill, a broad spectrum of organizations representing Canadians living with episodic disabilities launched a *Common Agenda on Disability, Full Participation and Work*.

“Existing programs were designed with permanently disabled people in mind. They don’t meet the needs of people with episodic disabilities,” said Francisco Ibanez-Carrasco, co-chair of the *Canadian Working Group on HIV and Rehabilitation* and a person who has been living with HIV for 20 years. “Without reform, many people with episodic disabilities will continue to lead lives characterized by income insecurity and poverty.”

“People with disabilities have a legal right to participate fully and equally in Canadian society. This means enabling people to work when they are able to work and providing easier, more flexible access to income support programs when they cannot”, said Glenn Betteridge, Senior Policy Analyst at the *Canadian HIV/AIDS Legal Network*.

The Common Agenda calls for long-overdue reform to both public and private disability income insurance and support programs – such as Employment Insurance sickness benefits, the Canada/Quebec Pension Plan disability benefit, long-term disability insurance, provincial social assistance programs, and health benefits. Increasing numbers of Canadians are living with episodic disabilities, including mental illness, mood disorders, cancer, lupus, multiple sclerosis, diabetes, and HIV/AIDS. One of the key distinguishing features of an episodic disability is its unpredictability, which can force people out of the workforce without warning, and then resolve itself and allow people to return to work. Workplace policies and income support programs do not adequately respond to the needs of these workers.

"Because the definition of disability is not consistent across all benefit programs, people who have a disease like multiple sclerosis are often left in the lurch," said Cheryl Elliott, a former nurse who has MS. "Symptoms like numbness, exhaustion and vision problems are invisible to the casual observer. The current system acts as a disincentive for people to apply for the disability benefits to which they are entitled."

Although there is currently some flexibility for people with episodic illnesses in public and private disability income support and replacement programs, these programs include disincentives that make it difficult for people with episodic disabilities to return to the workforce. The programs and their requirements are often communicated poorly to those who need them the most. The rules and decision-making processes are complex, not well publicized, and lack transparency.

Deanna Groetzinger, Vice President of Communications at the *Multiple Sclerosis Society*, states: “We applaud the newly introduced automatic reinstatement process for CPP disability benefits as an excellent first step. It is very important to people with MS to be able to contribute to their families and the community through meaningful work when they are well. MS attacks can happen any time. Having flexible policies in the workplace when receiving benefits and when attempting to return to work are vital.”

Ibanez-Carrasco explains: “our research shows that many people living with episodic disabilities fear losing their benefits if they try to return to work. This fear can act as a disincentive to explore opportunities to return to the workforce. Instead, programs should encourage people with episodic disabilities to work to their full potential. A multi-pronged strategy involving all stakeholders is needed to make this happen.”

The *Canadian Working Group on HIV and Rehabilitation* also presented several research reports, which explore the workplace and financial challenges many Canadians living with episodic illnesses face. These reports include:

- HIV & Disability Insurance in Canada: An Environmental Scan
- Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS: A Qualitative Study
- Looking Beyond the Silo: Disability Issues in HIV and Other Lifelong Episodic Conditions

All documents are available at www.hivandrehab.ca and www.aidslaw.ca.

-30-

Statement of Common Agenda on Disability, Full Participation & Work

In Canada today, many people live with recurrent or episodic disabilities that are characterized by alternating periods of illness and wellness. As stated in the Government of Canada response to the 2003 report *Listening to Canadians: A First View of the Canada Pension Plan Disability Program*: "recurrent and episodic disabilities are becoming more prevalent in Canadian society".

There are many systemic and practical barriers which prevent people with episodic disabilities from participating in the labour force, in communities, and in society in a meaningful way.

People living with disabilities have a right to participate fully and equally in Canadian society. Adequate income is an integral part of full participation.

People living with disabilities have a right to participate fully and equally in Canadian society.

Many people with disabilities rely on federal, provincial and private income support and replacement programs during periods when they are unable to participate fully in the workforce. However, certain aspects of these programs can act as disincentives to full participation.

In fact, the experience of many people with disabilities is that these programs trap them in poverty by creating barriers to staying on the job or returning to work. For people who live with episodic disabilities, this is especially true.

It is time that both public and private disability income support and replacement programs were reformed to meet the needs and aspirations of people living with disabilities.

We call upon the federal and provincial governments and private insurance companies to work with each other and with people living with disabilities to bring about long-overdue reform.

Signed,

- ARCH: A Legal Resource Centre for Persons with Disabilities
- Canadian Association of Nurses in AIDS Care
- Canadian Association of Physical Medicine and Rehabilitation
- Canadian AIDS Society
- Canadian Breast Cancer Network
- Canadian Cancer Society – Ontario
- Canadian HIV/AIDS Legal Network
- Canadian Working Group on HIV and Rehabilitation (CWGHR)
- COCQ-sida
- Lupus Canada
- Multiple Sclerosis Society of Canada
- Muscular Dystrophy Canada
- Ontario Breast Cancer Research Initiative

Statement of Common Agenda
on Disability, Full Participation & Work

BACKGROUNDER

OTTAWA - 4 May 2005

What is an episodic disability?
Episodic disabilities are characterized by periods of illness and wellness. Examples include mental illness, mood disorders, diabetes, cancer, lupus, multiple sclerosis, diabetes, and HIV/AIDS.

The Facts

- Recurrent and episodic disabilities are becoming more prevalent in Canadian society. – *Government of Canada response to the 2003 report Listening to Canadians: A First View of the Canada Pension Plan Disability Program.*
- Approximately half a million persons with disabilities are attached to the so-called system of income support in Canada. – *2001 Parliamentary Subcommittee on the Status of Persons with Disabilities*
- People in Canada living with disabilities earn less money than people without disabilities. In 2001, the average annual income for working age adults with disabilities was $22,451, compared to $31,509 for those without disabilities. Median annual income for working age adults with disabilities was $15,044, compared to $25,058 for those without disabilities. – *Statistics Canada, Participation and Activity Limitation Survey, 2001.*
- The unemployment rate of persons with serious mental illness reflects these obstacles and has been commonly reported to range from 70-90%, depending on the severity of the disability… productive work has been identified as a leading component in promoting positive mental health and in paving the way for a rich and fulfilling life in the community. Access to meaningful, paid work is a basic human right for every citizen, and those who experience serious mental illness should have equal access to the fundamental elements of citizenship. – *Canadian Mental health Association, Employment and Mental Illness*
- Nearly 80% of people with multiple sclerosis (MS) are eventually unable to work full time because of MS's severity and unpredictability. 25% percent have to change their employment status within 5 years of diagnosis; 50% within 10 years; and 80 percent within 20 years. Is the inability to work full time and participate in society a result of MS and its many symptoms, or because of societal barriers? Further work must be done to answer this question. – *Multiple Sclerosis from a Human Rights Perspective, Multiple Sclerosis Society of Canada presentation, February 2004.*
- There is a shared frustration with public and private insurance programs and policies that make it very difficult for people to qualify for benefits while entering and re-entering the workforce. Policies are rigid and unresponsive to the unique and ever changing circumstances of people living with episodic illness. People voiced the need for income protection that will carry them through periods of being well/unwell, working/not working, and part-time work. Most disability insurance policies and benefits do not make allowances for variable work patterns. – *P Proctor (2002). Looking Beyond the Silo: Disability Issues in HIV and Other Life-long Episodic Conditions, Final Report to the Canadian Working Group on HIV and Rehabilitation (CWGHR).*

- The status quo is a lose-lose proposition in the context of chronic illnesses with a fluctuating or uncertain course. Disability compensation plans lose because only a small sub-set of people living with HIV/AIDS will take a very risky leap in returning to work; people lose because they never get the opportunity to receive the added benefits of paid work. – *S Ferrier & J Lavis (2003) With health comes work? People living with HIV/AIDS consider returning to work. AIDS Care, Vol 15(3).*
- While symptoms and activity limitations are not "curable", innovative programs that help people living with HIV to adapt to their illness and keep them engaged in life are likely to have a significant impact on wellbeing. – *HIV Associated Disability among People Living with HIV in British Columbia, Results from the 2002 Survey Conducted by the BC Persons With AIDS Society in Collaboration with the BC Centre for Excellence in HIV/AIDS.*

Who we are and what we're doing

A broad network of organizations representing Canadians living with episodic disabilities is launching a *Common Agenda on Disability, Full Participation and Work*. The Common Agenda calls for the federal and provincial governments and the private sector to work together to reform existing public and private disability income support and replacement programs to meet the needs and aspirations of people living with episodic disabilities.

The following organizations have endorsed the *Common Agenda*:

- ARCH: A Legal Resource Centre for Persons with Disabilities
- Canadian Association of Nurses in AIDS Care
- Canadian Association of Physical Medicine and Rehabilitation
- Canadian Breast Cancer Network
- Canadian Cancer Society – Ontario
- Canadian HIV/AIDS Legal Network
- Canadian Working Group on HIV and Rehabilitation (CWGHR)
- COCQ-sida
- Lupus Canada
- Multiple Sclerosis Society of Canada
- Muscular Dystrophy Canada
- Ontario Breast Cancer Research Initiative

In-depth reports

- HIV/AIDS and Income Security (Legal Network): to be released this summer
- HIV & Disability Insurance in Canada: An Environmental Scan (CWGHR)
- Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS: A Qualitative Study (CWGHR)
- Looking Beyond the Silo: Disability Issues in HIV and Other Lifelong Episodic Conditions (CWGHR)

-30-

Contact: Elana Wright
Canadian HIV/AIDS Legal Network
Tel.: (514) 397-6828, ext. 259
Cell.: (514) 293-9533
Email: ewright@aidslaw.ca

Statement of Common Agenda
on Disability, Full Participation & Work

BIOGRAPHICAL NOTES

Glenn Betteridge, ***Canadian HIV/AIDS Legal Network***

Glenn joined the Legal Network in February 2003 as a Senior Policy Analyst. Glenn came to the Network from the HIV & AIDS Legal Clinic (Ontario) where he was a staff lawyer and acting legal director, representing low income people living with HIV/AIDS in housing, income maintenance, disability insurance, and human rights matters. He has also worked with federal and provincial prisoners, and advises AIDS service organizations. Glenn holds LLB and BCL degrees from the McGill Faculty of Law and is a member of the Ontario Bar.

Francisco Ibanez-Carrasco, ***Canadian Working Group on HIV and Rehabilitation***

Francisco Ibanez-Carrasco has been living with HIV for 20 years and experienced many of the return-to-work, income security, and rehabilitation issues that drive this project. He is one of CWGHR Co-Chairs and works as an HIV/AIDS Research Technical Assistant at the Community Based Research Capacity Building Program housed at the B.C. Persons With AIDS Society. He is also a faculty member at Goddard College, Vermont, US. He specializes in curriculum design and implementation, participatory qualitative methodologies, popular education, and health education.

Cheryl Elliott, ***Multiple Sclerosis Society of Canada***

A graduate of Dalhousie University with a Bachelor of Science in Nursing, Cheryl Elliott's primary focus of nursing care centred on individuals living with chronic illnesses such as pulmonary, cardiac and neurological disorders. After her own diagnosis of relapsing-remitting multiple sclerosis, she had to leave the nursing profession. Her commitment to helping continues with her work on the board and the education committee of the Ottawa Chapter of the Multiple Sclerosis Society of Canada. She takes as many opportunities as possible to speak to neurologists and other people with MS about living well with multiple sclerosis.

Eileen McKee, ***Canadian Working Group on HIV and Rehabilitation***

Eileen joined the CWGHR team in January 2005 as the Manager for the Project "Labour Force Participation and Social Inclusion for People Living with HIV and Other Episodic Disabilities". She brings extensive clinical and administrative experience from the addiction treatment sector, including as executive director of a treatment program. She has also worked a consultant for Ontario's Strategy to Combat Elder Abuse.

Statement of Common Agenda
on Disability, Full Participation & Work

SPEAKING NOTES

Glenn Betteridge

Good morning. Today, the Canadian HIV/AIDS Legal Network, the Canadian Working Group on HIV and Rehabilitation, the Multiple Sclerosis Society of Canada, and 9 other disability groups from across Canada are releasing a *Statement of Common Agenda on Disability, Full Participation and Work.*

My name is Glenn Betteridge, and I am a Senior Policy Analyst with the Canadian HIV/AIDS Legal Network. I will speak first, followed by:

- Francisco Ibanez-Carrasco, Canadian Working Group on HIV and Rehabilitation
- Cheryl Elliott, Multiple Sclerosis Society of Canada
- Eileen McKee, Canadian Working Group on HIV and Rehabilitation

In Canada today hundreds of thousands of people live with episodic disabilities – that is, disabilities characterized by alternating periods of illness and wellness. HIV/AIDS is an episodic disability – so are disabilities such as cancer, multiple sclerosis, diabetes, muscular dystrophy, lupus, and mental illness. Difficulties in maintaining an adequate and secure income, whether through employment or disability income programs, create major challenges for people living with episodic disabilities. For many people, having an episodic disability represents a downward spiral into poverty.

People living with HIV/AIDS and other episodic disabilities face significant obstacles to finding and retaining employment. The stigma of HIV/AIDS (and other disabilities) often discourages people from disclosing their condition to employers, and as a result work absences and decreased productivity may go unexplained. And rather than accommodating the person's disability, as is required by law, employers often treat work difficulties as job performance issues, which may lead to discipline or dismissal of employees with episodic disabilities.

Without regular employment, people living with HIV/AIDS and other episodic disabilities must rely on government and private programs for their income – such as Employment Insurance sickness benefits, the Canada/Quebec Pension Plan disability benefit, long-term disability insurance, provincial social assistance programs, and health benefits. These programs often perpetuate income *in*security.

Eligibility criteria that define disability in terms of "permanent" or extended unemployability make it difficult for people living with HIV/AIDS and other episodic disabilities to qualify for income programs. For those people who qualify, the programs effectively trap them in a web of rigid, inflexible, all-or-nothing rules. People who are healthy enough to contemplate returning to work are afraid to do so -- because of the fear of losing income and health benefits, fear being fired if they can’t step in and do the job full time full tilt, or fear of not having benefits reinstated in a timely manner if and when their health deteriorates.

This income *in*security is a source of stress and anxiety, which can impact on a person's ability to fully participate in work and other aspects of life. People living with episodic disabilities deserve better, have a right to better, to fully participate in Canadian society. And Canadian society deserves their full participation.

Francisco Ibáñez-Carrasco

Hello, I am Dr. Francisco Ibáñez-Carrasco; I work as the provincial HIV Community-Based Research Technical Assistant and I co-chair the Canadian Working Group on HIV and Rehabilitation.

- I arrived in Canada 20 years ago and acquired HIV shortly after, I was a 22 year old immigrant. My professional and personal lives are a testament that tenacity and treatment need to be combined with concerted rehabilitation efforts.

- For a large number of PHAs across Canada, having access to antiretroviral treatments has translated living with HIV/AIDS into a lifelong and episodic disability. "Active living" with HIV may include participating in sports, volunteerism and other social activities; however "paid work" is often perceived as a benchmark of adulthood and productivity in Canadian society. It is also known that income is a key determinant of health. Thus, an increasing number of PHAs have struggled to stay, or are considering entering or returning to the workforce.

- Twenty years ago I had little help on life planning or information about rehabilitation services. When an opportunistic illness hit me hard in 1993, I was completely unprepared. The 10 years that followed until 2003 were a roller coaster to regain physical emotional and mental strength, quality of life and to prepare myself for the workplace.

- For years I have seen people living with HIV and other disabilities make ends meet. Even after the advent of anti-retroviral drugs in 1996 it was difficult to make social workers and financial workers understand that one moves in a grey area. At times, one can study or work or volunteer, and at times one needs home care and meals on wheels.

- The rigidity of social services rules contrasted with the flexible efforts made by rehabilitation and health providers. This contrast still translates into a permanent undercurrent of anxiety and uncertainty. This, combined with lack of income security, makes for a life filled with apprehension. It feels like one's independence is always in somebody else's hands

- My participation in the episodic disability movement is motivated by a need to see substantial changes for those who have stayed in the workforce against all odds, those who had to leave and want to come back and the young persons living with disabilities who deserve a fair and equal chance at life planning, education, work, and participation in social and family life. There are many of us who are eager to contribute to Canadian society with our talents, energy, and taxes.

- Although the future of those who, like me, have joined the workforce somewhat “late” in life will be always be uncertain, there are organizations in BC that support its employees who live with disabilities. Disability programs and private insurers should support these employees. We are seeing that change has started to happen sporadically across the country. Some organizations and insurance companies are making flexible arrangements to accommodate us so we can efficiently contribute to the workforce.

- Creative, individualized solutions that ‘get people back to work’ are evidence of the potential for future “creative” arrangements between employers and PHA employees.

Cheryl Elliott

My name is Cheryl Elliott and I am here to tell you my experiences with multiple sclerosis and my attempts to remain in the work force.

First some background: I graduated in 1989 with a degree in nursing. Until 1998, when I was diagnosed with MS, I worked as a care manager in a community for people living with chronic illnesses including pulmonary, cardiac and neurological disorders. Because of my occupation, I was very much aware of the hardships people with medical illnesses face.

My first MS attack in 1998 left me paralyzed and I was forced to take leave from my job. I required the use of a wheelchair in subsequent months but in less than half a year, I recovered and was able to work again - displaying no *visible* signs of multiple sclerosis. However, the *invisible* signs of MS remained: numbness, susceptibility to exhaustion, episodic visual changes in my left eye and periodic weakness in my right arm.

Prior to my re-entry to the workforce, I was surprised that my employer did not make a single inquiry to determine what type of job would be best suited for my condition. When I did return, my employer informed me that they had replaced me and that I was going to be taking up a marketing role. More accurately, it was a sales position that required regular travel and constant movement in and out of the car. It was not a job that accounted for the specific needs of someone dealing from MS.

Within a month, the exhaustion that is a common byproduct of MS hit me and I was forced to leave my job.

Of course I had choices:

1) stay and sacrifice my health
2) work through the cumbersome and expensive legal system to get them to give me a more suitable job OR
3) the realistic choice for most people in my situation – leave my job and try to look for something better suited to my MS

In effect, I feel like I was systematically removed from a job that I loved.

I did try to find other work in my field. In fact, I would often make it to second round with only one other candidate left. In these second interviews, I did what I felt was honorable and appropriate: I told them I had MS. I wanted no surprises. I wanted to be upfront. I wanted people to know that there would be times, when yes, I would need time off because of an MS attack.

The repercussions of my honesty were jarring. Surreal moments would unfold as I sat in the interview room: I could see the jaws drop, the smile turn into a frown and any enthusiasm for my candidacy dissipate from the room. Unfortunately, this would happen time and time again. Now I was being fired from jobs I didn't have.

I can sum up my experience in three points:

- I had no input into the job I was going back to.
- The job I went back to was inappropriate.
- I was honest with potential employers but was discriminated against.

I do consider myself fortunate. I'm still able to live a relatively stable life and have a network of family and friends that support me. I know this is not the case for many and that is why real change in both policy and attitude needs to take place.

I support the Common Agenda on Disability, Full Participation and Work because it addresses the reality people in my situation face. I hope that governments, employers and insurance providers will sit up, take notice and most importantly, take action on these pressing issues.

Thank you for listening to my story.

For more information:
Stewart Wong, Media Relations
Multiple Sclerosis Society of Canada
Tel.: 416-967-3025
Email: stewart.wong@mssociety.ca

Eileen McKee

The message we have brought today is the culmination of three years of research at the Canadian Working Group on HIV and Rehabilitation in three reports: *Unpredictable Episodes of Illness in the Experiences of Persons Living with HIV/AIDS*; *Looking Beyond the Silo*; and today's release, *HIV and Disability Insurance in Canada: An Environmental Scan*.

This same message has been supported by the recommendations made by the Parliamentary Subcommittee on the Status of Persons with Disabilities, by the Statement of Common Agenda, signed by several participants of the Episodic Disabilities Network, by research undertaken by the Canadian HIV/AIDS Legal Network, and by other organizations across the country. The message is clear.

Episodic disabilities need not result in poverty and social exclusion. Today we call upon the federal and provincial governments and private insurance companies to work with each other and with people living with disabilities to bring about long-overdue reforms to benefit programs for persons with disabilities. My name is Eileen McKee and I am a Project Manager with the Canadian Working Group on HIV and Rehabilitation.

We will conclude with a list of directions for reform:

1. New, flexible definitions of disability that take into account the intermittent, reoccurring nature of certain diseases which often make it impossible for people to participate regularly in the workforce. Current definitions of disability are too narrow and are based only on permanent disabilities and permanent unemployability.

2. Common definitions of disability across programs, so applicants do not have to qualify for each and every program that they must rely upon to get the income and other benefits they need to live.

3. Transparent, consistent and principled disability adjudication, staffed by people knowledgeable about episodic disabilities and the impact of episodic disabilities on peoples' lives.

4. Programs that provide incentives to help people return to work, rather than leaving them in fear of losing income and other benefits if they try to do so. Pilot projects to test various approaches for return to work would be a good step forward. We do commend as an excellent initiative, the newly introduced automatic reinstatement provision for CPP disability benefit recipients. We also want to remind parliamentarians that the proposed budget contains needed changes to the tax system that will benefit people with all types of disabilities. We hope the legislation to implement these well-thought-out recommendations from the Technical Advisory Committee on Tax Measures for Persons with Disabilities will be passed.

5. Better communication with applicants and recipients of disability income security programs. Governments and private insurers need to communicate with people living with episodic disabilities where they are at – in terms of what they need to know, and how that information is presented. This includes the need for plain language materials and materials in languages other than English and French.