

DISABILITY RESEARCH BULLETIN

December 2000 – Vol. 1, Issue 1

A Message from the Office for Disability Issues

Welcome to the first issue of the *Disability Research Bulletin*.

The purpose of this bulletin is to disseminate information on the current status of disability research. Although this first issue includes only articles on disability research either conducted or sponsored by Human Resources Development Canada, the overall objective of the bulletin is to share information on

disability research among researchers from the wider disability research community. This may include, but is not limited to, disability organizations, research institutes, universities, non-profit organizations conducting research on disability issues, and other government departments and agencies at the federal and provincial/territorial levels.

We acknowledge that disability research involves a broad range of interests, each contributing to our understanding of the situation of persons with disabilities. Therefore, we invite you to submit articles that cover a variety of research interests relating to disability, such as socio-economic, rehabilitation engineering, independent living, health and transportation. Types of research may include qualitative, quantitative, pilot projects, etc. We hope that by making this publication increasingly representative of the various research fields, we can promote the complementarity among them.

Why distribute a bulletin on disability research? On many occasions, researchers and representatives from the disability research community have identified a need for more effective information sharing and networking around disability research. For example, in May 1999, a forum entitled "Research to Action: Working Together for the Integration of Canadians with Disabilities" was held in Halifax, Nova Scotia. At this forum, researchers, representatives of disability organizations and policy makers came together to review research findings, analyze results and plan for future research directions and policy change. Recommendations from the forum included the need to place more emphasis on the effective dissemination of research findings. This year, representatives from the disability community

CONTENTS

A Message from the Office for Disability Issues ...	1
About This Publication	2
RESEARCH REPORTS	
Update on the 2001 Post-Censal Survey	3
Supports for Higher Education: Spreading the Word About Best Practices.....	4
Price Survey on Disability Supports	4
Community Inclusion and Participatory Action Research, 2000-01	5
Connecting Our Realities: Women with Disabilities and the Need for Community-based Access to Technology	6
Canadian Injured and Disabled Workers: Coming Together	6
Evaluation of the Employability Assistance for People with Disabilities Initiative.....	7



again identified the importance of establishing support mechanisms to promote information sharing and the development of research as a critical element for capacity building.

This bulletin is designed to act as a first step in disseminating information on disability research. Future planning includes exploring the feasibility of the development of a Virtual Information Centre on disability research, through which information on

research projects and links to relevant Web sites would be easily accessible. A Virtual Information Centre will increasingly help people to more easily access the current status and findings of research that are being conducted across the country in various fields relating to disability.

About this Publication...

The *Disability Research Bulletin* will be produced twice a year by the Office for Disability Issues, Human Resources Development Canada. Information contained in the bulletin does not necessarily represent the position of HRDC or that of the Government of Canada.

Alternative Format

This document is available in English and French in either large print, audio cassette, braille or computer diskette. To obtain this publication in alternative format, call 1 800 788-8282. Requested documents are automatically produced in the alternate format selected and mailed directly to the requestor. This information is also available on HRDC's Internet site at: <http://www.hrdc-drhc.gc.ca/hrib/sdd-dds/odi/content/odipub.shtml>

Submissions

To submit articles on disability research, or to provide information on upcoming events relating to disability research, please forward submissions by **March 31, 2001** via e-mail (preferably in a Word document) to: odi-bcph@hrdc-drhc.gc.ca

Alternatively, submissions may be sent by mail or fax to:

Office for Disability Issues
25 Eddy Street, Suite 100
Hull, Quebec
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Fax: (819) 953-4797

Attention: *Disability Research Bulletin*

Comments, questions and changes/additions to the distribution list may be forwarded to the above e-mail or street address, or fax number.

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Update on the 2001 Post-Censal Survey

Development of the 2001 post-censal survey on disability-related issues is well under way. The lack of a comprehensive source of information since the 1991 Health and Activity Limitation Survey (HALS) has been widely cited as an impediment to progressive policy and program development, and the confirmation of funding in the February 2000 federal Budget signalled a strong commitment to action.

The Applied Research Branch (ARB) of Human Resources Development Canada has conducted an extensive consultation process to determine the information needs of the disability community, researchers and policy makers. The findings from this consultation have been published in a report entitled *Consultation on Disability Surveys*. The need for better information on disability supports was one of the major findings to emerge. The results have guided content development of the two questionnaires – one on adults with disabilities and the other on children with disabilities. Throughout this period, ARB has worked closely with Statistics Canada which will conduct the survey.

The findings from the 2001 survey will provide up-to-date information about the rate and types of disability, age of onset, need for and access to disability supports in everyday activities and within specific settings, educational attainment, employment status, costs related to disability and income levels.

The survey is now in the pilot-testing phase by Statistics Canada, to assess the content, clarity of the questions, suitability of the format, expected

response rates and the length of each questionnaire. Results of the pilot test will be evaluated and, based on the findings, decisions will be made as to the need for changes or modifications. The questionnaires will be finalized once this stage has been completed.

The Census of Canada will occur in May 2001 and the post-censal survey (which draws its sample from the census) will be conducted in September 2001. Results will be available in 2003. We will provide regular updates on preparations for the survey and the tabulation of the results in this space, so stay tuned!

For more information, click on HRDC's Web site at <http://www.hrdc-drhc.gc.ca/arb/disab/home.shtml>.

Supports for Higher Education: Spreading the Word About Best Practices

From August 1997 to October 1998, the Canadian Mental Health Association (CMHA) National Office conducted research to determine the support needs of students with psychiatric disabilities in higher education. Through a literature review, focus groups and interviews, the experiences of students and their support people were examined. This work has provided information on what people need to help them be successful in post-secondary education, what the most effective kinds of strategies are that support people can use, and how special needs policies might enhance the educational experience for students with mental health problems. The information has been documented in two resource materials. *Higher Education for People with Mental Illness* outlines the research findings and includes a more specific set of recommendations for policy makers. A second report, with tips and strategies for educators and other support people, is entitled *The Road to Empowerment: Following the Educational Path of University Students with Psychiatric Disabilities*.

In general, reports from past and current students indicate that supports in higher education are uneven at best. Getting the right kinds of support often depends more on chance than design, and many have found their best supports outside the formal educational system: from family, friends or other consumers. Other factors important for students and their families are good information, early identification and intervention, and support that is based on a foundation of faith in recovery and consumer control.

Based on this past research, CMHA has recently completed another project where a variety of strategies were used to gather, document and disseminate information about best practices for

supporting students with psychiatric disabilities in higher education, and to encourage action based on the information. Strategies have included producing and disseminating a **best practice guide**; holding **consultations** with mixed groups of students and educators/special needs offices at six colleges and universities across Canada to engage them in action strategies to implement best practice approaches to support; and **connecting with special needs offices** throughout Canada to disseminate materials and address their membership at conferences regarding best practice approaches to support.

For more information on this research project, and the next phase – using the Internet to promote the rights of students with psychiatric disabilities – click on CMHA's Web site at www.cmha.ca, under *Projects*.

This research is funded by the Social Development Partnerships Program, Human Resources Development Canada.

Price Survey on Disability Supports

The federal and provincial/territorial Ministers Responsible for Social Services have identified the need for development of policies to improve access to disability supports, to enhance the **portability** of these supports, and to help offset the **cost** of disability supports. However, the lack of data on disability supports limits the ability of governments to design and implement appropriate policies and programs.

To identify and fill such gaps in our knowledge, the Applied Research Branch (ARB) at HRDC has initiated a research strategy to develop a more

accurate picture of the living and working conditions faced by persons with disabilities in Canada. As one part of the strategy, ARB has launched a project to determine the prices of a range of disability supports.

The rationale for the price survey arises in part from the difficulty encountered by the 1991 Health and Activity Limitation Survey (HALS) in obtaining accurate figures for the cost of disability supports to the individual. An alternative method for obtaining accurate data about the costs of disability supports was needed.

A list of technical supports and services to be priced will be developed, and work will take place to ensure that the list corresponds to a coherent framework that is acceptable to the Canadian disability community. ARB is working with the Roeher Institute and Statistics Canada to carry out different aspects of this project. The Roeher Institute will prepare a conceptual framework of disability-related products, supports and services. It will also consult with members of the disability community to ensure that the framework is comprehensive and accurate. The list will include the supports asked about in the 1991 HALS and those listed in the *Income Tax Act* regulations for the Medical Expense Tax Credit.

The Consumer Price Index Section, Prices Division, of Statistics Canada will carry out a national price survey of commercial retailers, service providers and other sources of disability supports to obtain the selling price of goods and services. The goal is to create an objective and comprehensive national source of information about the prices faced by persons with disabilities, their families, and health and social service organizations.

Once completed in 2001, the price survey will contribute to the development of a more accurate and comprehensive portrait of the costs borne by individuals with disabilities, and will assist in the work

of researchers, policy makers, service providers, and advocates.

Community Inclusion and Participatory Action Research 2000-01

Canada's approach to social development has changed. Traditionally, helping professionals and service providers focussed on changing the individual, so that he or she would "fit" into the community. Now we are seeking to change whole communities, so that all may be included and participate to the fullness of their individual abilities.

In an effort to bring about this change for people with intellectual disabilities, the Government of Canada implemented the Community Inclusion Initiative. This initiative supports the development and implementation of strategies for communities to become more inclusive. Since its inception in 1997-98, Community Inclusion projects have involved 630 communities from coast to coast, the high arctic, and the south. It is estimated that 3,500 families and 7,400 individuals with disabilities have been directly involved in the activities of the initiative.

The Participatory Action Research process was launched in 1999-2000 as a tool for evaluating, analyzing, documenting and influencing social development initiatives in ways that are useful to communities, partners and stakeholders engaged in Community Inclusion. The current project builds on the existing action research process and will evaluate project progress, engage hundreds of participants across the country and create a continuous feedback loop to projects and Community Inclusion partners. This process will help to ensure successful outcomes, encourage opportunities for collaboration, and provide guidance and recom-

mendations for future Community Inclusion activity and policy formulation. The Canadian Association for Community Living will design and lead the process that will take place simultaneously at local, provincial/territorial and national levels.

This project is sponsored by the Social Development Partnerships Project, Human Resources Development Canada.

Connecting Our Realities: Women with Disabilities and the Need for Community-based Access to Technology

In an information age, technology is fundamental to everyday life. Access to computers, particularly the Internet, has become essential to personal independence and social connection for the individual. The isolation and exclusion experienced by women with disabilities in their ongoing struggle against barriers to education, meaningful work, and fulfilling social relations is further heightened by a lack of technological resources. Technology allows people to increase their knowledge, explore ideas and relationships, and develop creative and flexible work situations – opportunities that women with disabilities desperately need, but are often denied.

To address these needs, DAWN (DisAbled Women's Network) Canada is conducting a research project that seeks to identify communities of women with disabilities, document their technological needs, and ultimately propose workable solutions on local and national levels. A researcher will gather both quantitative and qualitative data from discussions and small group interviews, analyze responses, and prepare a report of preliminary findings. One of the initial outcomes of this project will be a series of accessible, plain language tools that women with disabilities can use to help increase their access to

and understanding of Internet resources.

Further initiatives to be explored include fully accessible computer-based training modules (CBTs) with plain language user interfaces designed to meet the needs of women with cross disabilities; fully accessible Web sites which will be able to accommodate various kinds of adaptive technologies, including voice recognition, large print, sound files and interactive graphics; and an Internet-based collective operated by women with disabilities.

For more information on DAWN's current research project, look for its final report which will soon be posted on its Web site at: www.indie.ca/dawn.

This project is sponsored by the Social Development Partnerships Program, Human Resources Development Canada.

Canadian Injured and Disabled Workers: Coming Together

Although many local injured and disabled workers' groups exist across the country, the Canadian Injured Workers Alliance (CIWA) has identified a need for the creation of more provincial organizations. By having strong provincial groups, injured workers across the country will have a larger role to play in future reforms to Workers' Compensation. Often, injured and disabled workers across Canada are not included in the planning for reforms, and they have faced reduced benefits and services as a result.

In CIWA's current research project, "Coming Together," 50 injured and disabled workers across Canada are sharing their experiences regarding the creation of provincial organizations, including past successes and failures. From these experiences, a "how to guide" is being developed. It will include

lessons learned and an analysis of why only some provincial organizations are successful. Meetings will then be held in those provinces where no such organization exists to introduce the guide and share experiences of working together to improve conditions for injured and disabled workers. Follow-up research may include further support for local efforts to move toward forming provincial organizations.

For more information on this research project, please contact CIWA at:
Phone: (807) 345-3429
E-mail: ciwa@norlink.net

This research project is funded by the Social Development Partnerships Program, Human Resources Development Canada.

Evaluation of the Employability Assistance for People with Disabilities Initiative

In early 1997, federal, provincial and territorial governments began working together to explore ways to improve and build on elements of the Vocational Rehabilitation for Disabled Persons (VRDP) program that had contributed most to labour market and economic participation. In late 1997, Ministers Responsible for Social Services approved a Multilateral Framework on Employability Assistance for People with Disabilities (EAPD).¹ In April 1998, the EAPD Initiative replaced VRDP with a stronger focus on employment for people with disabilities. The objective of EAPD is to help working-age adults

with disabilities prepare for, obtain and retain employment.

Under five-year bilateral agreements with all provinces, the federal government contributes 50 percent of the eligible costs of provincial programs and services, up to the maximum federal allocation. A Federal/Provincial/Territorial EAPD Working Group oversees the development, recommendation and implementation of multilateral activities.

Reporting and evaluation are important components of the accountability framework governing the implementation of EAPD. Bilateral agreements between the provinces and the federal government require ongoing evaluation of the programs and services cost shared under EAPD. Provinces may choose to conduct evaluation activities separately, bilaterally with HRDC, or multilaterally with HRDC and other jurisdictions. A Federal/Provincial Sub-Working Group on Evaluation² guides these activities.

EAPD evaluation work began by conducting an Evaluability Assessment. The assessment was conducted by an independent consultant, and was completed in February 2000. Its purpose was to gain a better understanding of the program elements, the clients being served, the delivery structure and data availability, and to identify options for evaluating EAPD-funded programs and services. Based on these options, the interests and capacity of provinces, the Federal/Provincial Sub-Working Group on Evaluation developed a joint evaluation work plan for 2000–01.³ Deputy Ministers approved this plan at their April 2000 meeting in Halifax.

¹ Quebec did not endorse the Multilateral Framework, although it has signed an EAPD agreement with the Government of Canada. There are currently no EAPD agreements with Northwest Territories, Yukon or Nunavut. Northwest Territories and Yukon, however, have endorsed the Multilateral Framework.

² Quebec does not participate on the Federal/Provincial Sub-Working Group on Evaluation.

³ Quebec is responsible for its evaluation.

The plan consisted of a "menu" of joint evaluation options from which provinces could choose in order to meet their evaluation needs,⁴ including multilateral and bilateral evaluation projects. Case studies of promising practices that provide information on positive approaches to promote employment and labour market attachment of people with disabilities and a longitudinal study of clients' progress in preparing for, attaining and retaining employment are operating as multilateral projects. Bilateral projects are tailored to the needs of particular provinces and can include feasibility studies, formative evaluations, case studies or surveys.

In the upcoming year, six provinces – Newfoundland and Labrador, Prince Edward Island, Nova Scotia, New Brunswick, Manitoba and British Columbia – have identified nine projects that will be part of the promising practices project. Three

provinces – Newfoundland and Labrador, New Brunswick and British Columbia – are participating in the longitudinal study. Three provinces – Saskatchewan, Alberta and British Columbia – are proposing to conduct bilateral studies. In addition, the federal and provincial governments are developing a generic evaluation framework. The results of these various evaluation projects will be available by March 2001 and will assist program managers in gaining a better understanding of the initiatives that have been reviewed.

For more information on these evaluation activities, please contact Chantal Paquette at (819) 953-7878 or chantal.paquette@spg.org.

⁴ Provinces may also develop evaluation activities apart from this menu of evaluation options.