



Central and Northern Region Data Collection

The IDSN Research Survey is currently underway. We are asking adults (19 years of age and older) living with an intellectual disability in the Central Region of Nova Scotia about their current and future health and social service needs, as well as their satisfaction with current services. To date, over 100 individuals have participated in the survey. We are planning to begin surveying again this spring/summer in both the Central and Northern Regions of Nova Scotia. We continue in our efforts to reach additional people who are currently receiving services within these regions, as well as those who are on waiting lists and those who are not accessing services.

If you are an adult living with intellectual disability in the Central or Northern Region and would like to participate in the survey, please phone our office at 457-6218 or email us at thepowerofknowing@msvu.ca.

In the Community

February 2010 : Dr. Norris gave a public presentation on collaborative learning in community-research alliances at the annual Research Open House at Mount Saint Vincent University in February.

April 2010: Dr. Hennen was a guest speaker on April 27th at a public discussion for caregivers with a son/daughter in junior high or high school with a physical disability, acquired brain injury or brain tumor. The purpose was to review Reviewing Housing Issues for People with Disabilities.



A Profile of Alliance Members

Brian Hennen, MD, MA, CCFP, FCFP, FRCGP, Co-Investigator



Dr. Brian Hennen is a current Professor of Family Medicine at Dalhousie University, as well as Professor Emeritus of the University of Western Ontario. He is also a family physician and medical graduate of Queen's University and he earned his Master's in Educational Psychology at Michigan State University. Dr. Hennen is the former head of the departments of Family Medicine at Dalhousie University and the University of Western Ontario and former Dean of Medicine at the University of Manitoba. He has served as president of the College of Family Physicians of Canada and as chair of the board of the Canadian Council of Health Accreditation.

Dr. Hennen was acknowledged by the University of Western Ontario Advisory Board in Developmental Disabilities and is the 1999 recipient of the Hull-Roehner Award of the Ontario Association on Developmental Disabilities for his work in the field of Developmental Disabilities. He conducts collaborative research on the prevalence of Developmental Disabilities with colleagues in Manitoba and Nova Scotia, the Capital Health District Authority and the Canadian Medical Association Journal.

Suzan Jorgensen, Community Partner

Suzan Jorgensen is a community partner on the Alliance representing the Disability Rights Coalition (DRC). The DRC was originally formed by advocates (individuals and groups) of cross-disabilities from across the province when the government commissioned Dr. Michael Kendrick to do a report on the state of disability needs in the province of Nova Scotia and subsequently make recommendations. Several years passed and the Kendrick Report was not implemented, but a core group of advocates continue to meet as issues arise. DRC member activity includes the distribution of communications and/or information, meeting with political representatives, and participation in panels, research projects, and media forums.



Suzan works full time in administration at the Capital District Health Authority, as well, she is a member of the Family Advisory Team to the Dalhousie Family Medicine Support Program for Primary Care to Adults with Developmental Disabilities and is a mother of a 28 year old daughter who has Angelman's Syndrome.

“Although my daughter has difficulty with her speech, gross and fine motor skills she enjoys a wide variety of activities, she has a terrific sense of humour and having fun whatever she does is her number 1 priority. I have advocated for my daughter her whole life and especially for her full inclusion in her community school. I am proud to say we had a successful experience, but even more important we had a true sense of belonging in our community.

Unfortunately, after high school there were no options for my daughter. Although she does attend a day program, this was not really a choice because it was the only place where support for her needs was funded. This was not our dream of 'belonging' in our community where there are no choices and flexibility is not an option. I realized then that I must actively do my part in advocating for the rights of individuals with disabilities in moving forward the possibility of having choices of work and where and who to live with.” **(S. Jorgensen)**



Thank You

Thank you to **Mount Saint Vincent University** for their ongoing support of this worthwhile research!

The Alliance successfully applied for a \$2500 internal research grant at MSVU to help assist with the development of a large-scale grant. If successful, the additional funding will be used to expand our survey to cover all regions within the province.

In addition to the internal research grant, MSVU has also approved our proposal for a \$7500 interdisciplinary research on human development grant. This grant will assist with costs related to a collaborative learning initiative between the IDSN Research Alliance and similar groups in Southeastern Ontario (South Eastern Ontario Community-University Research Alliance) and Manitoba (St. Amant Research Centre)

Fond Farewells



Erin Power, Project Coordinator, will be completing her position with the Alliance at the end of May to relocate to Cape Breton. Erin joined the Alliance in January 2007 and has offered valuable knowledge in administration, education and research to the project. In addition to the day-to-day coordination of the research, Erin, in collaboration with Alliance members, helped oversee the formation of the IDSN-RA logo, mission and vision statements, newsletter and website. She also coordinated data collection for both the pilot project and the central region to-date and program planning for the stakeholder workshop in October 2009.

"My work on the alliance has been very rewarding. The dedication that members show to the success of this research and the work that our community partners do to help improve the lives of persons living with an intellectual disability in Nova Scotia, their families and their communities is inspiring. I look forward to continuing to learn from the outstanding work of the Alliance and how we can all help to promote and support excellence in health and social services within our communities." **(E. Power)**

Priscilla Frenette, Project Assistant, completed her term as project assistant in February 2010. Priscilla provided valuable research assistance through literature reviews, data collection and analysis, events planning and public presentations. Priscilla will be dedicating the next couple of months to completing her graduate thesis with the Department of Community Health and Epidemiology at Dalhousie University.

The Alliance would like to thank both **Erin and Priscilla** for their exceptional contributions and wish them the best of luck in all future endeavors and continued work within the field!

Welcome to New Alliance Members

The Alliance would like to welcome its newest members, **Peter Nestman** and **Christen Terakita**.

Peter Nestman joined the Alliance in Winter 2010. Peter is the Interim Director of the Population Health Research Unit at Dalhousie University and brings to the Alliance an expertise in data management and health population research.

Christen joined the Alliance as a research assistant in March 2010. She holds a degree in psychology and is currently enrolled as a graduate student in the Department of Family Studies and Gerontology at Mount Saint Vincent University.

"My experience working with the Alliance has been fantastic! I have learned so much about services available in and around HRM that serve individuals with intellectual disabilities. I've also learned how important this database is in tapping into the real life needs and circumstances of Nova Scotians living with a disability. This work is so important and I am happy to be a part of it. I look forward to continuing on with the Alliance as a Graduate Research Assistant!" **(C. Terakita)**



Thank you to all the individuals and organizations who have offered their financial support, in-kind support, assistance, or interest to the Alliance.

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How to Contact Us?

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Intellectual Disabilities Service Needs Research Alliance

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Christen Terakita, Graduate Research Assistant

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Hilary Amit, Community Partner

Nova Scotia Residential Agencies Association

John Cox, Community Partner

People First Nova Scotia

Cathy Deagle Gammon, Community Partner

DIRECTIONS Council for Vocational Services

Suzan Jorgensen, Community Partner

Disability Rights Coalition

Mary Rothman, Community Partner

Nova Scotia Association for Community Living