

Welcome from our Alliance!

Welcome to the first edition of Alliance News!

We are an alliance of academics, not-for-profit service providers, advocacy groups, administrators and family members of persons with intellectual disabilities who are working toward developing a population-level database of information about Nova Scotian adults living with intellectual disability. Individuals living with intellectual disability and their families, service and advocacy organizations, government officials, and researchers have identified the development and use of a database of information about Nova Scotians with intellectual disability as a priority.

We invite you to browse through our newsletter to learn more about the project and feel free to contact us for further information.



Front Row (Right to Left): Dr. Deborah Norris, Mary Rothman, Cathy Crouse, Erin Power, Drea Arsenault;
Back row: Samantha Butler, Dr. Jancice Keefe, John Cox, Adele McSorley, Cathy Deagle-Gammon, Dr. Brian Hennen, Suzan Jorgensen, Dr. Kathy MacPherson, Dr. Gordon Flowerdew, Hilary Amit

Thank you to photographer Paul Darrow! www.pauldarrow.com/

Thank you to Summer Street Industries

Members of the Alliance are currently reviewing the results of the pilot survey recently conducted with the assistance of staff, volunteers, families, and community members at Summer Street Industries (Pictou County, NS) in July 2008.

The Alliance would like to sincerely thank the community of Summer Street Industries for their warm welcome, support of the project, and their continued assistance, suggestions, and feedback.

Results from the pilot project will help to refine the survey and surveying process that will be utilized to collect data throughout the Central Region beginning fall 2008.

About the Alliance

Our project has received three year funding from the Nova Scotia Health Research Foundation (NSHRF) to develop a comprehensive, sustainable, and linkable database that will profile the characteristics, health status, and met, unmet, and future health and social service needs of Nova Scotian adults (over 18 years) living with ID and their families/caregivers

The Alliance held consultations with the broader community in January 2006 through a Stakeholders' Forum. The focus and direction of the Forum was shaped by continuous input from all members of the Alliance. The guest list included persons living with intellectual disabilities, family members of persons with intellectual disabilities, university researchers, and representatives from service agencies, advocacy groups, and the Nova Scotia Departments of Health and Education.

The Forum was an overwhelming success, particularly because it assembled a diverse group of individuals who all worked toward a common goal: identify the components necessary to create a comprehensive and sustainable database of information about persons living with intellectual disabilities.

The consensus from the Forum was that the IDSN database should be person-centered and should address gaps in the existing information. Utilizing the feedback from stakeholders Alliance members were able to identify the primary objectives of the project.

Over three years, the objectives are as follows:

- Gather and articulate data that are currently available from government, industry, and advocacy organizations into a database
- Use the IDSN database to answer pressing research questions regarding the prevalence of Nova Scotians with an intellectual disability, their demographic profile, service needs and usage, satisfaction with services, and future needs
- Share research findings with: persons with intellectual disabilities and their families, policy makers, service agencies, advocacy groups, and researchers
- Implement a strategy to ensure the long-term sustainability of the database.

A key strength of our alliance is the active participation of our community partners: People First Nova Scotia, Nova Scotia Association for Community Living, the Disability Rights Coalition, Nova Scotia Residential Agencies Association, and DIRECTIONS Council for Vocational Services Society. At every major point, the community partners ensure that that the project is moving in a direction that will ultimately address the needs of persons with intellectual disabilities in a practical, respectful, and inclusive manner.

Answering questions about the health and social service needs and usage of

persons with an ID is integral to the health and well-being of Nova Scotians with intellectual disabilities. The IDSN database will not only address priorities identified by government, organizations and individuals and bridge the gap in current knowledge regarding the health and social service needs and usage of Nova Scotians living with ID, but also promote dialogue and support innovative and dynamic partnerships between persons with living with ID and their families/caregivers, government, educators, researchers and advocacy and service providers. The research of academics, policy analysts and health professionals who use the database will benefit from the practical insights and experience of our community partners. In addition, the capacity of the community partners to articulate research questions and use the data to inform their decisions about service planning, resource allocation, and advocacy work will be further advanced.

“When an influential political leader is asked to improve support for persons with developmental disabilities and asks ‘how many people are we talking about?’ and we, the experts, don’t have an evidence-based answer...we are obliged to determine one! That’s what this Alliance is about.”
Dr. Brian Hennen

A Profile of Alliance Members

Hilary Amit, M.Ed., Community Partner

Hilary Amit is a community partner on the Alliance representing the Nova Scotia Residential Agencies Association (NSRAA). The NSRAA is a coalition of non-profit (residential) agencies serving persons with disabilities. The NSRAA represents 44 not for profit community based service providers. Many of their members are also the main support to the families of persons with disabilities in their communities.

Hilary is the executive director of Highland Community Residential Services, a community agency with 110 paid employees providing residential and inclusion support services for people with developmental disabilities or mental health issues.

Hilary is the past president of the Nova Scotia Residential Agencies Association and is a member of the Nova Scotia Association of Social Workers. In 2003-2004 he served as a member of the board of directors of Nova Scotia's Health Care Human Resources Sector Council. Hilary holds a Masters Degree in Adult Education and a BA in Psychology (St. Francis Xavier University).



Deborah Norris, Ph.D., Principal Investigator

Deborah Norris, principal investigator on the Alliance, is Chair and Associate Professor within the Department of Family Studies and Gerontology at Mount Saint Vincent University. She has a PhD in Education and undergraduate and Masters degrees in Family Studies.

Deborah was the co-principal investigator on a project entitled Older Parents Caring for Adult Sons/Daughters with Disabilities: Age-Related Transitions funded by the NHRDP/CIHR from 1999 to 2001, a study considered to be a foundation for the current project.

Deborah teaches undergraduate courses in family relations, family life education, family and social theories, and family violence. At the graduate level, she teaches courses on critical theories and research methods.

For more than ten years, Deborah has been active as a qualitative researcher, but has employed mixed methodologies in a number of pro-

jects. In addition, her involvement in the family violence in the Canadian Forces' project, she has also acted as the principal or co-principal investigator on five externally funded projects focusing on family caregiving relationships with the military, the experiences of female military partners, and older parents caring for sons and daughters with lifelong disabilities. As an applied researcher, she commonly works with key informants from the community. Results of her work have informed the development of programs and policies that provide social support for families.



“The direction and insight of our dedicated community partners are integral to the continued success of our Alliance” Deborah Norris

About the IDSN Logo Design

After much dialogue amongst Alliance Members and assistance from Krista Beck, Communications Advisor, Public Affairs Office, MSVU and Carol Snow, Supervisor, Print Shop/Secretarial Services, MSVU, we are pleased to unveil our logo design.



The Alliance wanted to ensure logo colors were both positive and natural. We chose blue, green, and yellow; blue representing unity; green representing life and growth; and yellow representing optimism.

Similarly, the symbol of the sun itself represents a spirit of life, growth, and wellbeing. The spiral, forming the middle of the sun, speaks to the commitment that Alliance members have to learning and change, particularly that which emanates from the standpoint of those living with intellectual disability.



Congratulations to Drea Arsenault

Please join the Alliance in congratulating Drea Arsenault, Project Assistant, on her most recent accomplishments.

Shortly after being hired as a research assistant with the IDSN Research Alliance in May 2008, Drea graduated with a Bachelor of Science (Honours) from Mount Saint Vincent University. In July, she was honoured with a Certificate of Academic Excellence for her Honours Thesis (*It's All in the Details; Eye Witness Memory for Emotional Scenes*), from the Canadian Psychological Association.

Drea's work as a project assistant has been vital to the Alliance. Throughout the past couple of months she has assisted with stakeholder consultation, survey revision, and data collection and analysis.

Drea's work with the Alliance concluded at the end of August as she moved on to pursue graduate studies at the University of New Brunswick (UNB) in a combined M.A./Ph.D. program in Clinical Psychol-

ogy. Her graduate studies at UNB will be funded by a Canada Graduate Scholarship (CGS) Master's Scholarship awarded by the Social Sciences and Humanities Research Council of Canada, as well as a School of Graduate Studies Board of Governors Merit Award, a Graduate Research Assistantship and Graduate Teaching Assistantship.

The Alliance would like to thank Drea for her excellent work and wish her the best as she continues her studies!



What have we been up to?

Welcome to New Alliance Members

The Alliance would like to welcome its newest members Erin Power, Project Coordinator and Samantha Butler, Community Partner Representative.

Erin Power joined the Alliance as the Project Coordinator in January, 2008. Erin holds a Masters of Education in Adult Education from MSVU, a Masters of Public Administration (Public Policy) from Dalhousie University, and a Bachelor of Business Administration (Industrial Relations & Organizational Behavior) from Cape Breton University. Erin has worked as a research assistant on the Family violence: Applying lessons learned to elder abuse project, funded by Human Resources and Social Development Canada, as well as the Nova Scotia Gambling Research Project (NSGRP), funded by the Nova Scotia Gaming Corporation.

Samantha Butler joined the Alliance in February 2008 as a community partner representative from People First Nova Scotia. Prior to joining People First as the Support/Administrative Coordinator, Samantha was the Project Coordinator for the "Retirement Planning for Older Adults with Developmental Disabilities" through the Nova Scotia Community College. In addition, Samantha previously worked as the Inclusion Services Coordinator for Recreation with the Halifax Regional Municipality.

In the Community

February 2008

Workshop – Poverty and Intellectual Disability:

Alliance representatives had the opportunity to attend the [Poverty and Intellectual Disability Workshop](#) hosted by the Nova Scotia and Canadian Associations for Community Living in February 2008. The workshop was very insightful and provided a wonderful opportunity for community members to engage in dialogue about poverty issues.

March 2008

Health Policy Research Unit: Representatives from the Alliance attended an information session at Dalhousie University on March 6th regarding the proposed new Health Policy Research Centre. Further information regarding the new Centre may be found on the Nova Scotia Health Research Foundation website (www.nshrf.ca).

Provincial Network – Retirement Planning for

Older Adults: The IDSN Research Alliance was highlighted in the March 2008 edition of the [Provincial Network on Retirement Planning for Older Adults with Developmental Disabilities](#).

May 2008

United in Friendship Meeting: Alliance members hosted a meeting with members of the United in Friendship Group on May 6, 2008 in Pictou, NS. Members of the group reviewed the draft survey instrument and offered helpful advice on revisions. The Alliance would like to thank the United in Friendship Group, as well as Margie Beck and Hilary Amit, Highland Community Residential Services and Sheri Scott, Northern Region Respite Services, for their ongoing support and assistance.

In the Communitycontinued

Improving Primary Care to Adults with Developmental Disabilities: Members of the Alliance had the opportunity to attend a presentation by Dr. William Sullivan, Associate Professor of Family Medicine at University of Toronto and Primary Care Director of Surrey Place Centre in Toronto, on [Improving Primary Care to Adults with Developmental Disabilities Using Clinical Practice Guidelines](#) on May 22, 2008, hosted by the Department of Family Medicine, Dalhousie University.

Presentation at Cobequid Community Health Board's Annual Community Meeting: Members of the Alliance recently had the opportunity to present an introduction to the project at the Cobequid Community Health Board's Annual Community Meeting. We would like to thank the Cobequid Community for inviting us to present at their meeting and for their continued interest in our research.

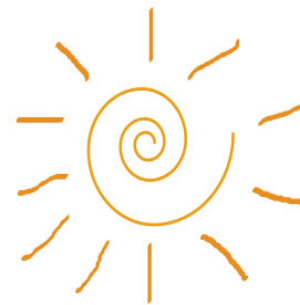
June 2008

Presentation at Chebucto West Community Health Board's Celebration Night: Members of the Alliance recently had the opportunity to attend a Celebration Night hosted by the Chebucto West Community Health Board. The celebration was held for community members/groups successful in applying for the 2008 Com-

munity Development Fund (CDF) Awards. Dr. Deborah Norris, Primary Investigator, had the opportunity to introduce the IDSN Research Project upon receiving a CDF on behalf of the Alliance. The Alliance would like to thank the Chebucto West Community Health Board for their financial support and ongoing interest in our research.

October 2008

Conferences: Alliance members are scheduled to participate in two upcoming conferences the St. Amant Conference, *Developmental Disabilities and Autism* in Winnipeg, MB (October 9-10), and the *Tools for Life Conference* in Greenwich, NS (October 23-24).



Alliance Members to Participate in St. Amant Conference

Two Alliance researchers are preparing to participate in the St. Amant Conference, *Developmental Disabilities and Autism*, in Winnipeg, MB in October 2008. Dr. Deborah Norris and Dr. Brian Hennen will present the results of the IDSN survey pilot and lessons learned as part of a multi-provincial panel presentation on the prevalence of developmental disabilities in Canada. Additional members of the panel include Shahin Shoostari, PhD, Assistant Professor/Researcher, Department of Family Social Sciences and Community Health Sciences, University of Manitoba & St. Amant Research Centre; H el ene Ouellette-Kuntz, BScN, RN, MSc, Epidemiologist at Ongwanada, Associate Professor, Department of Community Health & Epidemiology, Director, Southeastern Ontario Community-University Research Alliance in Intellectual Disabilities, Queen's University; and Marni Brownell, PhD, Associate Professor, Department of Community Health Sciences, Senior Research, Manitoba Centre for Health Policy, University of Manitoba.

Supporting Adults with Chronic Illness or Disabilities

Researchers from the Hidden Costs / Invisible Contributions (HCIC) program recently released a report, *I Wish That I Could Just Have a Break*, which discusses the consequences of supporting adults with chronic illness or disabilities.

The HCIC team is an international group of scholars lead by Dr. Janet Fast, Acting Chair and Professor, Department of Human Ecology, University of Alberta, who have been working closely with project partners from government, community and various not-for-profit organizations since 2003 to explore the costs and contributions of older adults and adults with chronic health problems or disabilities. Dr. Janice Keefe (MSVU), IDSN Co-Investigator, participates as a co-investigator for the HCIC project.

To learn more about the HCIC Program and to read the final report, please visit their website: www.hcic.ualberta.ca

Thank you to Community Groups

Thank you to the **Chebucto West Community Health Board**, **DIRECTIONS Council for Vocational Services**, and **Nova Scotia Residential Agencies Association** for their recent financial contributions to the project.

These donations will support the Alliance in a diversity of project-related activities, including data collection, and analysis, stakeholder consultation, and ongoing awareness raising and education.

The Alliance continues to seek funding opportunities to support project objectives, as well as to promote the sustainability of the database to ensure the accessibility of reliable information about adults living with intellectual disabilities in Nova Scotia for years to come.



Tools for Life Expands to Two Day Event

GREENWICH - The third annual Tools for Life Conference and Exhibit has expanded to a two-day event on October 23rd and 24th 2008. The conference encompasses children, youth, adults and seniors with a focus on overcoming barriers at home, in the workplace and community. It showcases non-profit organizations, businesses, government agencies and educational institutions offering exhibits and presentations for the public on wellness and independent living, literacy and lifelong learning, employment and careers, and assistive technologies for all ages and abilities.

Advance registration is required and space is limited to 300. For further information, please visit www.tools4life.ca or Email: tfl2008@eastlink.ca.

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

A special thank you to our primary funding agency, the Nova Scotia Health Research Foundation, for their ongoing support and assistance.



How to Contact Us?

Phone: 902-457-6218
Email: thepowerofknowing@msvu.ca

Mail:
IDSN Research Alliance
c/o Erin Power, Project Coordinator
Nova Scotia Centre on Aging
Mount Saint Vincent University
166 Bedford Highway
Halifax, NS Canada B3M 2J6

Intellectual Disabilities Service Needs Research Alliance

Dr. D. Norris, Principal Investigator

Family Studies & Gerontology, Mount Saint Vincent University

Dr. K. MacPherson, Co-Principal Investigator

Community Health & Epidemiology
Faculty of Medicine, Dalhousie University

Dr. G. Flowerdew, Co-Investigator

Community Health & Epidemiology
Faculty of Medicine, Dalhousie University

Dr. B. Hennen, Co-Investigator

Department of Family Medicine
Faculty of Medicine, Dalhousie University

Dr. J. Keefe, Co-Investigator

Maritime Data Centre for Aging Research & Policy Analysis
Family Studies & Gerontology, MSVU

Cathy Crouse, Associate

Metro Community Housing Association

Adele McSorley, Associate

Centre of Excellence on Children and
Adolescents with Special Needs, MSVU

Pam Talbot, Associate

Diabetes Care Program of Nova Scotia

Erin Power, Project Coordinator

Mount Saint Vincent University

Hilary Amit, Community Partner

Nova Scotia Residential Agencies Association

John Cox & Samantha Butler, Community Partners

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

Population Health Research Unit (DAL), Associate Agency