



The Intellectual Disabilities Service Needs Research Alliance is comprised of a collaboration of academics, not-for-profit service providers, advocacy groups, administrators and family members of persons with an intellectual disability who are working towards developing a population-level database of information about Nova Scotians living with an intellectual disability.

To date, no single, comprehensive collection of information exists in NS to profile this population's needs. Smaller collections of data are available from various agencies; for the most part, these sources fall into two categories: survey data and administrative data. The potential exists to integrate these sources of information into a cohesive and comprehensive database that would have a number of applications: improving the quantity and quality of available information on persons with an intellectual disability, increase capacity to address fundamental research questions relative to the prevalence of Nova Scotians with an intellectual disability, their demographic profile, service needs and usage, satisfaction with services, and future needs.

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 an intellectual disability and their families/caregivers.

Over three years, the objectives to achieve this goal 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 intellectual disability 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 an intellectual disability, but also promote dialogue and support innovative and dynamic partnerships between persons with living with an intellectual disability 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.

Contact

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Thank you