

Stakeholders' Forum

Intellectual Disability Service Needs Research Alliance

January 6, 2006

Forum Report

March 2006



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Acknowledgements

In October 2004, a community alliance of researchers, service agencies, and non-profit advocacy groups joined together to identify and assess the components, existing and required, of an on-going system designed to collect and make available publicly information on the service needs of Nova Scotians with intellectual disabilities and their families/caregivers. The Stakeholders' Forum held on January 6, 2006 was a key component of this process.

The Intellectual Disability Service Needs (IDSN) Research Alliance would like to thank all Forum participants who generously gave their time and expertise to make the day possible. The guest list included individuals with intellectual disabilities; family members of persons with intellectual disabilities; representatives from service providers, advocacy groups, and government; as well as university researchers.

This event was made possible through the financial support of the Nova Scotia Health Research Foundation and the in-kind support of the Centre of Excellence for Children & Adolescents with Special Needs – Early Intervention Task Force, the DIRECTIONS Council for Vocational Services Society, the Kendrick Report Coalition, the Nova Scotia Association for Community Living, the Nova Scotia Residential Agencies Association, and People First Nova Scotia.

Executive Summary

This report summarizes the proceedings of the Stakeholders' Forum hosted on January 6, 2006 by the Intellectual Disability Service Needs (IDSN) Research Alliance. The Forum provided a venue for persons with intellectual disabilities and their family members, service providers, advocacy organizations, government representatives, and university researchers to assess existing sources of information about persons with intellectual disabilities, identify gaps in the information that is available, and discuss how to address these gaps through the development of an on-going information gathering system.

Although there is no single, comprehensive collection of information (or data) about persons with intellectual disabilities, smaller collections are available from various agencies. The potential exists to integrate these sources of information into a cohesive and comprehensive database. This type of integrated information system would have a number of applications which include advocacy, planning and evaluating services, and informing policy decisions. However, before such a system can be developed, some obstacles must be addressed; these include agreeing on a common definition of intellectual disability and developing compatible data collection and storage strategies. It is important to recognize that a system based on currently available information would only collect information about individuals who are receiving or who have received services. Other strategies need to be devised to collect information about individuals who have never received services.

Forum participants identified two major categories of information that should be included in the information system: data on individuals with intellectual disabilities and data on services that are available to this population. The consensus from the Forum was that the information should be person-centred, which necessitate the use of a unique identifier like a health card or social insurance number. The information system should also address gaps in the data that are currently available. Items suggested for inclusion include: supports and services that are needed – both now and in the future; supports and service that are wanted; and satisfaction with approach to care, supports and services, and service providers.

An on-going, integrated information system has numerous applications within the community. Service providers could use the information to plan how to use their limited resources to best meet the needs of their community – being proactive rather than reactive. The information also allows service organizations to be held accountable for their use of funds and their provision of appropriate services. Facts and figures generated from an on-going information system can be used by advocacy organizations when they lobby for the rights of individuals with intellectual disabilities and their families/caregivers. Currently, these groups must rely on anecdotal information, something that is not always useful to policy makers.

The development of an on-going, sustainable information system depends on the collaborative effort of key stakeholders including individuals with intellectual disabilities and their families/caregivers, advocacy groups, service providers, government, and researchers. Part of the infrastructure necessary for such a system includes protocol for sharing information about the project; agreements relating to intellectual property, ownership of information, and publication of findings; policies for the storage, sharing, and destruction of data; and ethical standards. Other components of the infrastructure are more concrete – data collection instruments, computer hardware and software, and a data storage site.

The task that lies ahead is to submit a proposal seeking funds for three years so that the IDSN Research Alliance can develop and implement an on-going information gathering system. Although the task is challenging, it is possible. Similar systems are being created and used in difference contexts both nationally and internationally.

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1.0 Introduction

Individuals with intellectual disabilities and their family members, service providers, non-profit advocacy groups, and university researchers joined together to form the Intellectual Disability Service Needs (IDSN) Research Alliance. The unifying factor behind this alliance is a shared desire to address a fundamental problem in the delivery of supports to Nova Scotians with intellectual disabilities – a lack of high quality, reliable information about the characteristics, current service use and satisfaction, and future service needs of this population. Such information is integral to the responsive, equitable, and sustainable provision of services and to informed decision making and policy planning.

The purpose of the Stakeholders' Forum was to engage the broader community in identifying and assessing the components (existing and required) of an on-going system designed to collect and make available publicly information about Nova Scotians with intellectual disabilities and their families/caregivers. The day was a resounding success. In total, 13 IDSN Research Alliance members and 21 guests representing persons with intellectual disabilities and their families, service providers, advocacy groups, and government departments participated in the discussions. The pages that follow are a summary of the day's deliberations. These ideas will guide the IDSN Research Alliance in the development of a research proposal to devise and implement the system and begin gathering information on the population characteristics, current service use and satisfaction, and future service needs for individuals with intellectual disabilities and their families/caregivers.

2.0 Information Sharing: Literature & Currently Available Data

Currently, there is no single comprehensive collection of information (or data) about individuals with intellectual disabilities. Instead, smaller bits of information exist in many different places. For the most part, these sources fall into two categories: survey data and administrative data. Combining these existing sources of information into an integrated system would provide a basis for conducting research to inform policy and planning decisions that affect individuals with intellectual disabilities and their families/caregivers. However, some obstacles must be overcome before integrating these data sources.

2.1 Sources of Information

2.1.1 Survey Data

Surveys purposefully collect information about a given topic. For example, Stats Canada collects information about persons with disabilities through the large scale national survey known as the Participation and Activity Limitations Survey (PALS). A wide variety of information is collected through this survey including type and severity of disability, activity limitations, health, housing, employment, education, income, and service needs. Once collected, this information can be used to answer many different research questions. For example, the Disabled Persons Commission uses information from the PALS to prepare its statistical report on Nova Scotians with disabilities. Although the PALS is a very useful source of data on disability, it is limited in that it only collects information on individuals living in private dwellings or non-institutional group settings.

At a local level, the DIRECTIONS Council surveyed the 28 vocational centres in Nova Scotia. The primary focus of the survey was the actual vocational centres; however, some useful information about persons with intellectual disabilities was also collected (e.g., the percentage of clients whose

primary diagnosis is an intellectual disability, the age profile of clients, and the years of service profile of clients).

2.1.2 Administrative Records

Generally, administrative data are collected to meet the needs of a particular organization or agency rather than for research purposes. However, this information can be very useful in research. The Population Health Research Unit (PHRU) at Dalhousie University houses many different sets of administrative records from both the Department of Health (DoH) and the Department of Community Services (DCS) as well as data from some national and provincial surveys. Importantly, PHRU has the capacity to link records from various sources by using unique identifiers derived from encrypted health or social insurance numbers.

Some major sources of administrative information about individuals with intellectual disabilities that are collected by government departments include the following:

- **Department of Community Services:** records on Community Services Pharmacare, the In-Home Support Programme, the Early Intervention Programme, the Income Supports Programme, & Community Supports for Adults with Disabilities
- **Department of Education (DoE):** records from the Rehabilitation Programs and Services Division (provides support for Nova Scotian students with disabilities) and information about children in grades K-12 who are on Individual Programme Plans (key identification point for children with intellectual disabilities, brain injury, autism spectrum disorders, etc.)
- **Department of Finance (DoF):** Community Counts
- **Department of Health:** MSI Physician Services, Hospital Discharge Abstracts, and Continuing Care
- **Business Reports for Government Departments:** aggregate data on specific populations and services

Other sources of administrative information about individuals with intellectual disabilities include the following:

- **Nova Scotia Residential Agencies Association:** 100+ item survey distributed to 44 residential agencies (can be merged with DIRECTIONS Council survey) and agency waitlists
- **DIRECTIONS Council:** survey of 28 vocational centres and centre waitlists
- **Western Region Research Project:** Collaborative research project with DoE, DCS, and service providers
- **Other possible sources: the Department of Justice, Autism Groups, Community-based Agencies, Independent Agencies, and the Special Olympics**
 - These sources need to be identified, contacted, and asked if they have and are willing to share information about individuals with intellectual disabilities
 - A number of resources exist to aid in identifying these organizations:
 - NSNET (<http://www.nsnet.org/>)
 - SNIS Directory Online (<http://www.snis.ca/>)
 - Persons with Disabilities Online (<http://www.pwd-online.ca/pwdhome.jsp?lang=en>)
 - People Places Programs (<http://www.nsnet.org/leo/peopleplacesprograms/>)

2.2 Obstacles to Integrating Data Sources

Although there are many sources of information about individuals with intellectual disabilities, some obstacles must be overcome before these sources can be integrated into a cohesive and comprehensive information system. Problems identified during this session include the following:

2.2.1 No Common Definition of Disability

This problem is not unique to Nova Scotia or even Canada. The problem is so widespread that the United Nations (UN) assembled a special working group to examine the issue. This group recently drafted a framework for collecting information on disability that uses neutral language. Within this framework, impairment is defined as a reduction in the function of a body part or organ (e.g., amputated leg), disability is defined as a reduction in the function or activity of a person (e.g., cannot walk), and handicap is defined as resulting from a social context that places a person with an impairment and/or disability at a disadvantage compared to others without the impairment and/or disability (e.g., cannot go to a movie because theatres are not wheelchair accessible). The UN working group is using this framework to develop questions to collect internationally comparable information about individuals with disabilities. Essentially, this group is engaged in the same work that we propose to do; that is, developing an information gathering system. They just have a broader focus – all disabilities rather than intellectual disabilities and the world rather than Nova Scotia.

Defining intellectual disability raises another issue – the use of labels. Some individuals prefer not to use labels, which may ultimately result in their not receiving services. Some organizations may also refrain from using labels. For example, the education system does not use the label intellectual disability – as a result, a proxy measure for intellectual disability must be used. For example, one can reasonably infer that an intellectual disability is present if a child is on an Individual Programme Plan (IPP). However, not all children on IPPs have intellectual disabilities, and some children with intellectual disabilities may not be on an IPP.

2.2.2 Inconsistent Data Collection & Storage Strategies

Some information sources use unique identifiers like a health card number or social insurance number whereas other sources of information do not. The value of a unique identifier is that it allows a person to be followed through one or several systems (i.e., person-centred data), and it helps prevent the double counting of individuals who access multiple services. The drawback is that it creates a situation in which the anonymity of an individual may be compromised.

2.2.3 Capturing Individuals Who “Are Not Being Served”

It is important to remember that administrative records only capture information on individuals with intellectual disabilities who are accessing at least one service. If an individual is not accessing any services, there will be no record of that person's need. The only way to collect information about such persons is through a population-level survey, a method that can be both costly and time consuming.

3.0 Breakout Session I: Gaps in Existing Data & Ways to Fill Them

3.1 What Information Do You Need?

To decide what information is needed, we first must identify the purpose of the information. What questions do we want to answer? Why do we need the information? If this step does not occur, we may gather information that never gets used, resulting in a less efficient information gathering system. We also need to consider how the information will be analysed. It should be collected in such a way that it can be broken down in to various levels – provincial, regional, and local. Thought also should be given as to whether the information should be longitudinal (ongoing – collected across time) or cross-sectional (snapshot – collected at one time). For example, a person-centred approach requires longitudinal information.

Two broad categories of information were identified as important: information about individuals with intellectual disabilities and information on services for individuals with intellectual disabilities. The areas of interest are listed below.

3.1.1 Information about Individuals with Intellectual Disabilities

- Number of persons with intellectual disabilities
 - Number with dual or multiple disabilities
 - Number with chronic health problems
- Demographic information
 - Age, sex, residence, income, education, training, culture/ethnicity (e.g., First Nations, Acadian), and religiosity (e.g., faith community, spiritual community)
- Communication abilities
 - Language – Oral and written
 - Literacy
 - Computer literacy
- Abilities & Competencies – capacity
- Present & future goals – transition times
- Services
 - Needs – part of life-long continuum of care – plan for the future
 - Received – in past and at present
 - Not received – Why? – lack of information, availability, eligibility, choice, etc.
 - Unmet need – disparity between services needed and services received

3.1.2 Information on Services for Individuals with Intellectual Disabilities

- Relevant research – local, provincial, national, and international
 - Best practices
- Available services
 - How are they defined, accessed, and funded

- Who can receive them
- Satisfaction with services – individual, family, and caregiver
- New service needs – responding to a changing population
- Family support needs

3.2 What Are the Gaps?

Although information about individuals with intellectual disabilities and their service needs is currently being collected by various organizations, there are a number of gaps. Some gaps relate to the individual, some to services for persons with intellectual disabilities, and some to the broader community. The perceived gaps identified by Forum participants are listed below.

3.2.1 Gaps in the Information about Individuals with Intellectual Disabilities

- Some persons with intellectual disabilities are not identified as having an intellectual disability
- Some persons with intellectual disabilities are not receiving services
 - Some have never received services
 - Some are waitlisted (some waitlists are not active)
 - Some are not waitlisted
- Some persons with intellectual disabilities are difficult to locate
 - Immigrants and refugees
 - Homeless and transient
 - Isolated
- Service for persons with intellectual disabilities
 - Supports and services that are needed – currently and in the future
 - Supports and services that are wanted/desired – which requires a knowledge of the continuum of service options (currently available and future possibilities)
- Satisfaction with services – individual, family, and caregiver
 - Types of supports and services
 - Approach to care
 - Service provider
- Personal history
 - Especially important for individuals who are being cared for at home – if family members/caregivers become ill or pass away, the personal information about the individual being cared for may be permanently lost

3.2.2 Gaps in the Information on Services for Individuals with Intellectual Disabilities

- Innovative service options – realm of possibilities – what could be
- Best practices
- Policy and procedures – e.g., level of education required to work for service provider

- Process evaluation
- Disincentives to using services
- Communication and coordination of services

3.2.3 Gaps in the Information about Communities

- Cultural demographics
 - Cultural understanding
-

4.0 Panel Discussion: Benefits of an On-going Information System

4.1 Nova Scotia Residential Agencies Association (NSRAA)

The NSRAA has 44 agencies throughout Nova Scotia, each of which has a board, at least one administrator, and some staff – a resource that could be used in the development of an on-going information system. One agency in the NSRAA, the Highland Community Residential Services (HCRS), currently has a waitlist of approximately 40 individuals. However, this list has not been validated in the last four years because HCRS “does not want to raise the expectations of the people on the list.”

An on-going information system would be a tremendous tool for the member agencies of the NSRAA. At the most basic level, this information system would inform NSRAA members about the number of individuals with intellectual disabilities in their communities and the current and future needs of these individuals. With this information, NSRAA members could plan how to use their limited budget to **best** meet the needs in their communities – keeping their services relevant to current and future clientele. A more comprehensive information system could be used to keep NSRAA members accountable – both in their use of funds and their provision of **appropriate** services. This system could also be used for education – although NSRAA members provide residential services, people sometimes contact them for knowledge and support.

4.2 Nova Scotia Association for Community Living

The NSACL is an advocacy group for persons with intellectual disabilities and their families/caregivers. Unfortunately, without hard facts and figures, the advocacy role of the NSACL is hindered. Currently, the NSACL must rely on anecdotal information, which is not always useful to policy makers. The proposed on-going information system would help the NSACL do a better job by providing concrete evidence to back up anecdotal accounts. With on-going access to current information, the NSACL would never be in a position in which they have to say to government officials or parents of children with intellectual disabilities, “We do not know how many people we are talking about (i.e., people with intellectual disabilities).”

4.3 People First Nova Scotia (PFNS)

People First Nova Scotia is a self-advocacy group for people who are labelled with an intellectual disability. There are eight chapters in Nova Scotia: Annapolis, Halifax/Dartmouth, Kings County,

Sydney, Truro, Windsor, Wolfville, and Yarmouth. Most members receive social assistance and some receive supports through the Services for Persons with Disabilities (SPD) Division of the Department of Community Services (DCS). Ironically, some people are “disabled” enough to receive income supports, but are “not disabled” enough to qualify for supports through SPD – both programmes are administered through DCS. An on-going information system would help PFNS advocate for better and more appropriate services for its members.

4.4 DIRECTIONS Council

The DIRECTIONS Council is comprised of 28 vocational centres in Nova Scotia. These vocational centres are more than buildings with four walls – they are part of the community. In order to respond to the needs in their communities, the directors of these centres need information about those they serve and those they could be serving. Currently, these centres are forced to be reactive rather than proactive. An on-going information system would enable the directors of vocational centres to be better visionaries – allowing services to evolve and break away from a cookie-cutter approach. Moreover, this information could be used to change policy and political will – knowledge is power.

5.0 Breakout Session II: Building an On-going Information System

5.1 Preliminary Work

Before an on-going information system can be developed, a number of preliminary tasks must be completed. Some of these issues are being addressed now; others must be addressed in the near future.

5.1.1 Literature Review

Obviously, we do not want to reinvent the wheel. As such, reviewing the literature pertaining to both individuals with intellectual disabilities and information systems is essential. This task is currently underway. Some sources that were mentioned at the Forum include the NSRAA Legislative Review, the Western Region Research Project, and Understanding the Early Years. All of these sources have been retrieved and are under review. Some literature on the concept of social capital has also been identified and is being reviewed.

5.1.2 Identify Key Stakeholders

The success of our proposal depends on the support of various groups – individuals with intellectual disabilities and their families/caregivers, advocacy groups, service providers, government, and researchers to name a few. Our alliance already includes a diverse group of community partners and university researchers. The Forum was a vehicle to bring in another layer of stakeholders – a broader spectrum of service providers and advocacy groups as well as government representatives. Through this process, some other potential stakeholders were identified – physicians, K-12 education system, and the Department of Justice.

To ensure the long-term sustainability of this project, we must develop a document that outlines the roles and responsibilities of stakeholders. This document should include protocol for sharing information about the project; agreements relating to intellectual property, ownership of information, and publication of findings; and ethical standards.

5.1.3 Identify Purpose of Information Collection

A vast amount of information could be collected through the proposed system; however, we should not just collect information because we can. One way to guard against the collection of extraneous information is to identify the purpose for the information we want to gather. Some questions to guide this process follow:

- Are we interested in individuals or systems or both?
- What is the purpose of the data – surveillance, future planning, and/or policy development?
- What questions do we want to answer?
- Who are the end users?

5.1.4 Define Key Terms

The development of the proposed information system will require input from various agencies and organizations. To facilitate this process, agreement on common definitions is essential. Fortunately, there is precedence for this task. The United Nations is currently drafting a framework to define in a consistent manner terms such as impairment, disability, and handicap. In order to develop an on-going information gathering system, many other definitions would have to be clarified. Some of these include intellectual disability, service, service need, service models, health conditions, and population of interest. Importantly, these definitions must use plain, neutral language. Once developed, these definitions need to be shared with the various stakeholders and the general public.

5.1.5 Select a Model for the Information System

A number of models exist for the development of an information system; it can be person-centred, system-centred, or a combination of both. The system can also be local, regional, provincial, or national in scope. Also, we might wish to position the model within a theoretical framework. For example, if we want to situate the information gathering system within a social capital framework, we would need to collect information about individuals, social capital within the community, and how individuals use of the social capital available to them.

5.2 Components of an Information System

5.2.1 Infrastructure

If we are going to collect information, we need a place to store it. Most likely, it will be stored in a computer database. However, depending on the collection strategy, we also may have to store manual files. When establishing a database, we need to consider how the information will be used. If we want to track individuals' trajectories through the system, we need access to individual level information. Individual level information can always be collapsed so that aggregate level information can be reported to or shared with other agencies.

We will also need instruments through which to gather the information. By consistently using standardized instruments and data collection protocol, we can ensure a reasonable level of quality control. In order to decide on relevant instruments, we should consider who will be supplying the information. For example, do we want self-assessments or professional assessments or both? If we use only self-assessments, we may wish to devise a strategy to verify the information that is given.

5.2.2 Contributors and Users

For the most part, the contributors and users of information about individuals with intellectual disabilities are the same. The following table provides a synthesis of the possible contributors and

users of an on-going information system, giving examples of what information could be contributed and how the information could be used.

Individuals, family, and caregivers	Contributor	Information about demographics, service needs, and satisfaction
	User	Learn about services, access services, and plan for future
Service and advocacy organizations	Contributor	Information on who uses services, how often, and why
	User	Share information, plan for future, evaluation of services, inform policy, and accountability
Government	Contributor	Information about health, education, income, and employment; who uses services, how often, and why
	User	Share information, plan for future, evaluation of services, inform policy, and accountability
Researchers	Contributor	Develop data collection instruments and protocol
	User	Analyse data, share information, evaluation of services, and inform policy
Data Manager	Contributor	Existing or new independent entity

5.3 Process of Gathering Information

An information system is only as good as the information entered into it. As such, it is important to keep the information collection as simple as possible. Achieving this simplicity might require separate systems for individuals and agencies. For example, individuals might be able to enter information about themselves using a touch screen similar to an Automated Teller Machine (ATM). Such a system would be easy for both adults and children, even those who have difficulty with gross and/or fine motor control. Symbols could be used to facilitate understanding for those who have difficulty reading.

An important aspect of the information gathering process is the decision to use or not use a unique identifier. A unique identifier is necessary to gather person-centred information and to guard against double counting of individuals. If a unique identifier is used, protocol must be developed to ensure the privacy of the individuals providing information. Using explicit questions about how the information can be used might be a viable option. The Canadian Community Health Survey includes items that seek individuals' permission to share their survey responses with their province and to link their responses with past and future administrative records.

Finally, a concerted effort should be made to identify individuals with intellectual disabilities who are not receiving services. By following a specific cohort (age group) of individuals through the K-12 education system and then through the vocational/residential system, it might be possible to determine how many individuals do not receive any services as adults. Having an indication of how many people are not receiving services is the first step in developing a strategy to identify and contact them.

6.0 Next Steps: Working Together to Create a Proposal

The task that lies ahead of us is to develop a workable system of data collection that will benefit persons with intellectual disabilities and their families/caregivers, service providers, advocacy groups, policy makers, and government. In May 2006, we will submit a Collaborative Health Research Project Grant to the Nova Scotia Health Research Foundation (NSHRF), asking for three years of funding during which time we will test our proposed data collection model.

It is a daunting task – to create a sustainable system to gather information on the population characteristics and current and future service needs (and wants) of people with intellectual disabilities, their families, and caregivers. However, it is possible. In fact, on-going information gathering systems are being created and used in other contexts: the Newfoundland Centre for Health Information, Understanding the Early Years (a national initiative), the Offord Centre at McMaster University, and the West Australia Intellectual Disabilities Database to name a few.

A key to overcoming the obstacles to this project is anticipating them. Some obstacles that could work against the development of an on-going integrated information system include the following:

- Agency or organizational needs may take precedence over collaborative work
- Gaps in information are relatively defined – meaningful data to one agency may be unnecessary or intrusive “noise” to another
- A highly complex system can be susceptible to technical glitches
- The continuity of the system may be affected if a key individual leaves an organization
- It may be necessary to reorient service delivery so the consumer is at the centre

Although there are some potential barriers to the proposed system, there are also many factors working in our favour. Chief of these factors is the interest displayed by IDSN Research Alliance members and Forum participants. Other facilitating factors include the following:

- Information exchange has worked informally between departments and organizations
- Computer software and the internet have revolutionized information management
- The re-examination of citizenship and roles of individuals, families, and government transcends party politics – it recognizes our obligation to include everyone
 - Canada is a signatory to UN Declaration on the Rights of Disabled Persons
- An on-going information system is a logical component of a person-centred and community-based model of service delivery
- There is a movement toward outcome-based evaluation of services

7.0 How Can I Get Involved?

In the coming weeks, the IDSN Research Alliance will draft a proposal based on current literature and information shared through the Stakeholders' Forum. By the end of MArch, the IDSN Research Alliance will be in a position to make a presentation on the proposed information system to your agency, organization, or department. Such a presentation will help keep you informed about our progress and will give us the opportunity to receive valuable feedback on the proposed system. It is our sincere hope that you will join in our vision by sharing your ideas and by writing a letter of support to be submitted with our application for funding.

Appendix A – Glossary of Acronyms

DCS	Department of Community Services
DoE	Department of Education
DoF	Department of Finance
DoH	Department of Health
HCRS	Highland Community Residential Services
IDSN	Intellectual Disability Service Needs
IPP	Individual Programme Plan
MSI	Medical Services Insurance
NSACL	Nova Scotia Association of Community Living
NSHRF	Nova Scotia Health Research Foundation
NSRAA	Nova Scotia Residential Agencies Association
PALS	Participation and Activity Limitation Survey
PFNS	People First Nova Scotia
PHRU	Population Health Research Unit
SNIS	Special Needs Information Service
SPD	Services for Persons with Disabilities
UN	United Nations

Appendix B – Project Summary

Identifying the Service Needs of Persons with Intellectual Disabilities

Background

The need to collect high quality data on the population of individuals with disabilities is receiving attention at provincial, national, and international levels. Such data are integral to informed decision making and policy planning. Here in Nova Scotia, the government is shifting from an institutional-care model to a community-care model of service delivery in an effort to provide a “fair, equitable, responsive and sustainable” system of supports for Nova Scotians with intellectual disabilities. To make this transition as smooth as possible, it is essential to know the answers to some basic questions:

1. How many Nova Scotians have an intellectual disability?
2. What are the current population characteristics of Nova Scotians with intellectual disabilities?
3. Are these population characteristics likely to change over time?
4. What services are currently available for persons with intellectual disabilities and their families/caregivers?
5. Are these available services adequate?
6. What additional services are needed?
7. How will changing the type and delivery of these services affect persons with intellectual disabilities and their families/caregivers?

Our community alliance of researchers, service agencies, and non-profit advocacy groups aims to identify and assess the components (existing and required) of an on-going system designed to collect and make available publicly information on the service needs of Nova Scotians with intellectual disabilities and their families/caregivers. Once this preliminary information is gathered, our alliance will develop a research proposal to implement the system and begin gathering information on the population characteristics, current service use and satisfaction, and future service needs for adults with intellectual disabilities and their families/caregivers.

Through the current project, we will increase our understanding of the available information and its limitations regarding the numbers, characteristics, and service needs of persons with intellectual disabilities and their families/caregivers within Nova Scotia. This knowledge then can be used to inform planning and policy decisions that affect the on-going health and community care needs of these individuals. Ultimately, this information will be used to help people with intellectual disabilities fulfill their potential for independence and community participation.

Primary Interest Groups

1. Adults with intellectual disabilities and their family/caregivers
2. Service providers and advocacy groups for adults with intellectual disabilities and their family/caregivers
3. NS Departments of Community Services, Education, and Health

Goal of Current Initiative

Identify and assess the components necessary to create a comprehensive and sustainable information system designed to provide publicly available information on the aggregate service needs of persons with intellectual disabilities and their family/caregivers in Nova Scotia

Steps to Achieve Goal

1. Use specified criteria (e.g., study design, validity, reliability) to review and synthesize available literature describing the population characteristics and service needs of persons with intellectual disabilities and their family/caregivers **(on-going)**
 - Describe population characteristics and service needs of persons with intellectual disabilities and their family/caregivers
 - Describe limitations and gaps in existing literature
2. Use specified criteria (e.g., recency, accuracy, accessibility) to assess existing data sources kept by community and government organizations **(on-going)**
 - Describe nature and scope of existing data on persons with intellectual disabilities and their family/caregivers
 - Describe limitations and gaps in existing data
3. Hold Stakeholders' Forum to discuss the necessary components of a sustainable system for gathering quantitative and qualitative data on persons with intellectual disabilities and their family/caregivers **(early January)**
4. Collaboratively design the information gathering system **(early February)**
5. Develop and submit a Collaborative Health Research Project Grant proposal for funding to implement the information system for the May 2006 NSHRF 2006 grant competition **(mid March)**

Appendix C – Forum Agenda

Intellectual Disability Service Needs Research Alliance Stakeholders' Forum January 6, 2006

Agenda

<i>Time</i>	<i>Item</i>
10:00 - 10:15	<i>Registration</i>
10:15 - 10:35	<i>Introductions</i> <ul style="list-style-type: none">• <i>Cathy Deagle Gammon</i>
10:35 - 10:45	<i>Introduction to the Project</i> <ul style="list-style-type: none">• <i>Deborah Norris</i>
10:45 - 11:05	<i>Information Sharing: Literature & Currently Available Data</i> <ul style="list-style-type: none">• <i>Pam Talbot</i>
11:05 - 11:50	<i>Breakout Session I: Identify Gaps in Existing Data & Ways to Fill Them</i> <ul style="list-style-type: none">• <i>Cathy Crouse, Janice Keefe, & Chris Murphy</i>
11:50 - 12:30	<i>Review Outcomes from Breakout Session I</i> <ul style="list-style-type: none">• <i>Cathy Deagle Gammon & Deborah Norris</i>
12:30 - 01:00	<i>Lunch</i>
01:00 - 01:30	<i>Panel Discussion: Benefits of an On-going Information System</i> <ul style="list-style-type: none">• <i>Hilary Amit, John Cox, Cathy Deagle Gammon, & Mary Rothman</i>
01:30 - 02:15	<i>Breakout Session II: Steps to Building an On-going Information System</i> <ul style="list-style-type: none">• <i>Cathy Crouse, Janice Keefe, & Chris Murphy</i>
02:15 - 02:30	<i>Afternoon Break</i>
02:30 - 03:15	<i>Review Outcomes from Breakout Session II</i> <ul style="list-style-type: none">• <i>Cathy Deagle Gammon & Deborah Norris</i>
03:15 - 03:45	<i>Next Steps: Working Together to Create a Proposal</i> <ul style="list-style-type: none">• <i>Adele McSorley</i>
03:45 - 04:00	<i>Closing Remarks & Evaluation</i> <ul style="list-style-type: none">• <i>Cathy Deagle Gammon</i>