

# **Intellectual Disabilities Service Needs Research Alliance**

## **Workshop Summary**

**December 12, 2009**



**IDSN**  
**Intellectual Disabilities Service Needs**  
**Research Alliance**



## 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-ongoing system designed to collect and make available publicly information on the service needs of Nova Scotians with intellectual disabilities. A community Stakeholders' Forum was held on January 6, 2006 to identify the key components of a data collection instrument and database for this system. A survey was developed, based on feedback from the Stakeholders' Forum and a series of consultations with IDSN Research Alliance Members and key community stakeholders, and piloted at Summer Street Industries in Pictou County, Nova Scotia. The pilot survey helped to identify key areas of revision for both the survey process and design. Upon revision, the survey was distributed throughout the Central Region with the assistance of local service organizations. To date, over 100 individuals with intellectual disability have participated in the survey. The Stakeholders' Workshop hosted by the IDSN Research Alliance on October 15, 2009 provided an opportunity for the researchers to update stakeholders' on the results of the survey to-date, elicit feedback on current initiatives and discuss potential research questions.

The Intellectual Disabilities Service Needs (IDSN) Research Alliance would like to thank workshop participants who generously gave their time to make the day possible. The guest list included individuals living with an intellectual disability, family members, service providers, advocates and university students and researchers.

This event was made possible through the financial support of the Nova Scotia Health Research Foundation, the DIRECTIONS Council of Nova Scotia, the Regional Residential Services Society, and the Chebucto-West Community Health Board; as well as the in-kind support of the Nova Scotia Centre on Aging and IDSN Research Alliance Community Partners.

## **Executive Summary**

This report summarizes the proceedings of the Stakeholders' Workshop hosted on October 15, 2009 by the Intellectual Disabilities Service Needs (IDSN) Research Alliance. The workshop provided a forum for persons with intellectual disability, family members, service providers, advocates, and university researchers to discuss the ongoing work of the IDSN Research Alliance.

Members of the Alliance presented a summary of the survey process employed to collect information on the health and social service usage, needs, and gaps from adults living with intellectual disability in Nova Scotia, as well as a summary of key themes emerging from the data collected between June and October 2009.

Workshop participants identified a number of key research issues for consideration during a series of facilitated workshops throughout the day. Suggestions for survey design included the use of plain language and converting the online survey to larger and darker font. Participants suggested paying particular attention to potential conflicts of interest and question bias during data collection, as well as addressing issues of trust. Key areas of research that participants felt would be helpful to them included, access to health and social service, access to affordable recreation options, access to affordable and reliable transportation, urban/rural experiences, and access to affordable and nutritious food. The importance of employing a diversity of advertising tools to encourage participation and to reach the hidden population was discussed. Finally, participants noted the value in continuing to update all stakeholders on the work of the IDSN Research Alliance and providing evidence of the potential outcomes of this work for all stakeholder groups.

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## **Introduction**

Individuals living with intellectual disabilities and their family members, service providers, non-profit advocacy groups, and university researchers joined together to form the Intellectual Disabilities 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.

With the assistance of five community service organizations, a previously piloted survey instrument was administered to 109 individuals living with intellectual disabilities in the Central Region of Nova Scotia between June and October 2009. The survey was designed to capture current and future service needs and gaps in four domains: personal and social environment, educational and employment services, residential setting, and health and well-being. Following data collection, a workshop was held to bring together researchers, service providers, individuals living with intellectual disabilities and their families. In total, 10 IDSN Research Alliance members and 31 guests participated in the day's events. The specific purposes of the workshop were to present preliminary research findings to those involved in the survey administration, to discuss improvements to the survey process, to ascertain what information would be useful to interested stakeholders, and to discuss future directions for the IDSN project. These objectives were met through presentations, small and large group discussions, and networking breaks. This document summarizes the themes that arose from the day's discussions, themes that will shape the future directions of the project.

## **Presentation of Emerging Themes**

Dr. Deborah Norris, Principal Investigator, Erin Power, Project Coordinator, and Priscilla Frenette, Graduate Research Assistant presented a power point summary of the overall survey process used by the IDSN Research Alliance and key themes prevalent within the data collected between June 2009 and October 1, 2009. Key service issues in areas such as recreation, education, employment, residential services, and health care were discussed (See Appendix A – Power Point Handouts).

## **Breakout Sessions**

Participants were divided into small groups to share their thoughts/ideas on the IDSN survey and what information would be useful to them as stakeholders. In addition, advice was elicited on how the Alliance could encourage participation and reach the hidden population.

## ***Breakout Session 1***

### **1. In your opinion, what are the strengths and weaknesses of our survey process?**

Group facilitators received positive feedback for the overall research project and the Alliance as a research group. The level of participation by each stakeholder group within the workshop and the overall research was well received.

Discussion regarding the survey itself elicited some very practical information that will assist with updating the survey and evaluating research methods. Participants recommended using as much plain-language as possible and to use bigger and darker font in the online survey. Participants liked the use of visual props in the survey, however, some felt that the ‘happy/sad faces’ could be more obvious in expression. Some participants were concerned with the invasiveness of some of the questions; however, others felt that it was clear that respondents could choose not to answer questions they were not comfortable with.

All stakeholders expressed their concern over potential survey bias. For example, some participants indicated that respondents may not be comfortable discussing how they feel about the service they are receiving when it is service providers surveying them. On the other hand, some participants felt that knowing the data collect would help to elicit more open answers. Another example provided for potential survey bias was the difficulty that data collectors may encounter when trying to distinguish between the opinions of the respondent from those of the support person (survey respondents were provided with an option of having someone with them of their choosing for support during the survey). Service providers also suggested adding a way in which questions could be flagged if the data collector or support person knows that the data being provided is inaccurate. In addition, some participants felt respondents may have a difficult time answering questions that focus on the future.

Additional issues that participants offered for consideration were shortening the survey and addressing mistrust of the system and potential reluctance to sign research consent forms.

### **2. What questions would you like answered? How would this information be useful to you?**

In general, participants felt the survey questions on health and social services were good. Participants shared a great deal of issues they would like to be addressed through our research, including:

- Access to and cost of transportation. Participants stressed the importance of evaluating how transportation affects everything in one's life, including employment, health, social network, safety...etc.
- Access to and cost of nutritious food / food security
- Access to and cost of recreational activity
- Respondents opinion on how they feel about their community and their jobs
- Types of jobs held by respondents and rate of pay/income
- Comparative analysis of the experiences of persons living in rural environments to those in urban environments
- Inequality in services (e.g. some clients fully funded for transportation needs and others are not)
- Early intervention
- Service needs of indigenous adults living with intellectual disability

Participants felt that this data would assist them in determining what is working and what is not. They also indicated that the data could potentially be used to develop education tools for service providers, funding agencies, care coordinators, and government.

## ***Breakout Session 2***

### **3. How can we encourage people or service organizations to participate in the survey?**

Participants felt that the best way to encourage active involvement is to engage in ongoing communication with all stakeholder groups and continue to provide evidence of where and how the research is or will be making a difference.

Participants also emphasized the importance of advertising. A diversity of advertising methods was suggested, including:

- Community partners of the Alliance sponsoring information nights (e.g. Café night), while being mindful of transportation issues.
- Print advertisements in community newspapers and posters in libraries and job search centers
- Radio/media
- Community presentations
- Write-ups in organization newsletters
- Face-to-face and word-of-mouth networks
- Care coordinators
- Attend local conferences and enlist participants (Tools for Life and NSRAA regional conference)

- Provide more information directly to care-givers/families
- Providing rewards to participants and data collection agencies, such as sponsoring/hosting a social event

In addition to advertising and ongoing feedback, participants encouraged researchers to be mindful of the limited resources of the data collection/service agencies. Creative approaches to data collection were encouraged, such as training university students to conduct the surveys.

The importance of building trust within the community was underscored. In particular, it was suggested that more reassurance was needed around the use of health card numbers and the fear of labeling through data analysis.

#### **4. How can we reach adults with intellectual disability who are not currently receiving services?**

The importance of utilizing different methods to advertise the work of the IDSN Research Alliance was discussed. In particular, participants identified the following potential community outlets:

- Through doctor's offices and the hospital (Doctors NS)
- School system
- Faith community bulletins
- Community newspapers
- Special Olympics
- Waiting lists
- Organizational communication lists (NSACL / People First)
- Distribution of information by key government departments
- Community centers

Participants also indicated that it is important to understand how stakeholders will gain access to the database when it has been fully developed.

### **Next Steps: Working Together to Create an Accessible, Reliable, and Sustainable Database**

The task that lies ahead of us is to develop a workable database that will benefit persons with intellectual disabilities and their families/caregivers, service providers, advocacy groups, policy makers and government.

One key challenge in creating a workable database system is finding sustainable funding. The IDSN Research Alliance is currently working on a number of funding proposals that will allow us to expand data collection beyond the current boundaries of Central Region, NS and Pictou County, NS.

## How Can I Get Involved?

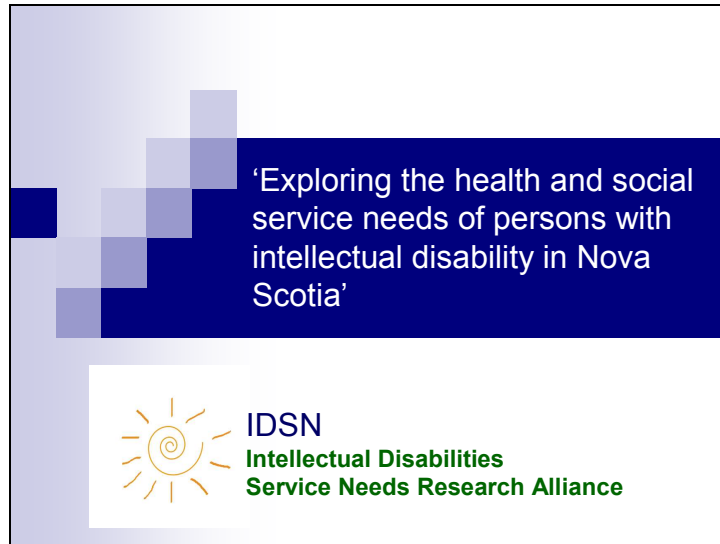
Over the next year, the IDSN Research Alliance will continue to collect data in collaboration with all stakeholders. Alliance members will continue to check-in with stakeholders to provide an update on the status of the project and how the survey is progressing and to request feedback.

As a stakeholder, we hope that you will continue to share your feedback and ideas with the Alliance either through participation at community events or by contacting us directly through email ([thepowerofknowing@msvu.ca](mailto:thepowerofknowing@msvu.ca)) or by phone (902-457-6218).


If you or someone you know would like more information on our survey or research, or would like to participate in the survey, please feel free to contact us.

## Appendix A – Workshop Presentation 2009

Slide 1

The slide features a dark blue header with white text. Below the header is a white box containing a logo of a sun with rays and the text 'IDSN Intellectual Disabilities Service Needs Research Alliance'.

'Exploring the health and social service needs of persons with intellectual disability in Nova Scotia'

 IDSN  
Intellectual Disabilities  
Service Needs Research Alliance

Slide 2

The slide has a white background with a blue gradient bar at the top left. The title 'Who are we?' is centered in blue. The main text is in blue and describes the organization's mission.

**Who are we?**

The **Intellectual Disabilities Service Needs Research Alliance** is a group of researchers, service providers, and advocates who are working towards developing a database of information about the current and future health and social service needs Nova Scotians living with intellectual disability.

Slide 3



## Who is involved? Researchers

**Mount Saint Vincent University:**

- Dr. Deborah Norris, Lead Researcher
- Dr. Janice Keefe, Researcher

**Dalhousie University:**

- Dr. Kathy MacPherson, Co-lead Researcher
- Dr. Gordon Flowerdew, Researcher
- Dr. Brian Hennen, Researcher

**Associates:**

- Erin Power, Project Coordinator
- Adele McSorley, Associate
- Cathy Crouse, Associate

Slide 4



## Who is involved? Community Partners

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
- DIRECTIONS Council for Vocational Services Society
- Independent Living Nova Scotia

Slide 5

## The Survey

The information that people share with us in the survey will help better plan for current and future health and social service programs.

It will also provide government with the information they need to improve policies that affect persons with intellectual disabilities and their families and caregivers.



Slide 6


## General Questions

- What are the current health and social service needs of Nova Scotians with intellectual disability?
- What services are they receiving?
- How satisfied are they with these services?
- What services do people need that they aren't getting?
- What services will they need in the future?

Slide 7

## Data Collection

- Survey Development – Extensive consultation with stakeholders and all Alliance members
- Recruitment of data collection agencies throughout Central Region, Nova Scotia
- Training data collectors within these organizations (confidentiality, survey methods, and informed consent)



Slide 8

## Data Collection Agencies – To-Date

Five organizations with the Central Region of Nova Scotia (Halifax, Dartmouth, Sackville, and Sheet Harbour):

1. **Dartmouth Adult Services Centre** - A vocational day program for adults with an intellectual disability.
2. **Anchor Industries Society** – Provides individualized vocational and recreational day options to adults with intellectual challenges.
3. **Gerald Hardy Memorial Society** – A vocational day program for adults with an intellectual disability.

Slide 9

### Data Collection Agencies – To-Date


4. **New Leaf Enterprises** - A program of the Abilities Foundation of Nova Scotia. Focus is on developing job skills for adults with physical disabilities.
5. **Regional Residential Services Society** - offers a variety of residential choices that support adults with intellectual disabilities



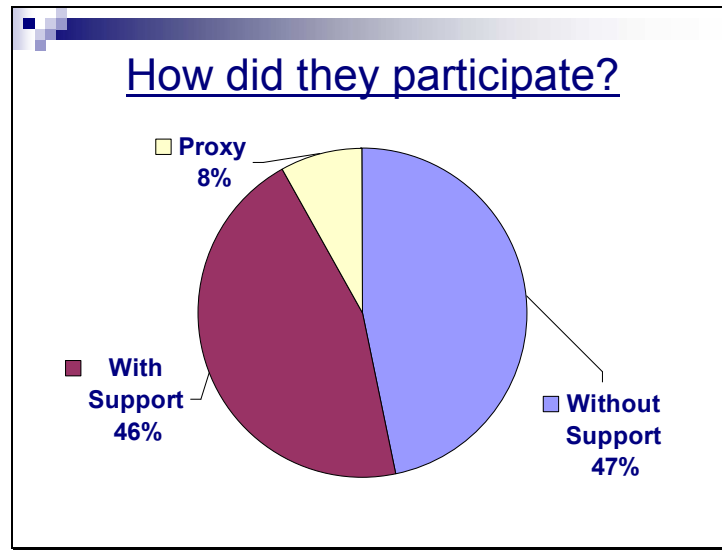
Slide 10

### Who took the survey?

- 50 Men
- 59 Women
- 97% were single, never married



Slide 11




Slide 12

- ### School / Education
- Many individuals surveyed said they finished an education program: public school, individual program plan, vocational school, training program, and others.
  - Most people said they are not currently taking any classes

## School / Education


Of the people that are taking classes, the most common ones are:

- Computer Training
- Literacy Classes
- Fitness Classes
- Art / Drama Classes



## School / Education

- A little over half of the people surveyed indicated that they had access to a computer on a regular basis



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Slide 15

## Employment

- 91% of people said that they had a job (56% full time & 35% part time)
  
- Job Type:
  - For Pay (minimum wage or higher) – 8%
  - Supported Work – 11%
  - Volunteer Work – 9%
  - **Adult Day Centre / Vocational Agency – 62%**
  - Self-employed – 1%

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## Employment

- 50% of the people said that they were very happy with their job and 23% said they were happy with their job
  
- When asked about their job, some of the top answers included:
  - Happy with and proud of job
  - Enjoy working with co-workers
  - Happiest when job involves many activities
  - Not enough jobs
  - Not enough pay

## Social Network

A little over half of the people surveyed said they **do not** see their friends and family as much as they would like to


The top four reasons why:

- Friends & family aren't available as often as they would like
- Difficulty finding transportation
- Not enough money
- Need help from another person to get out

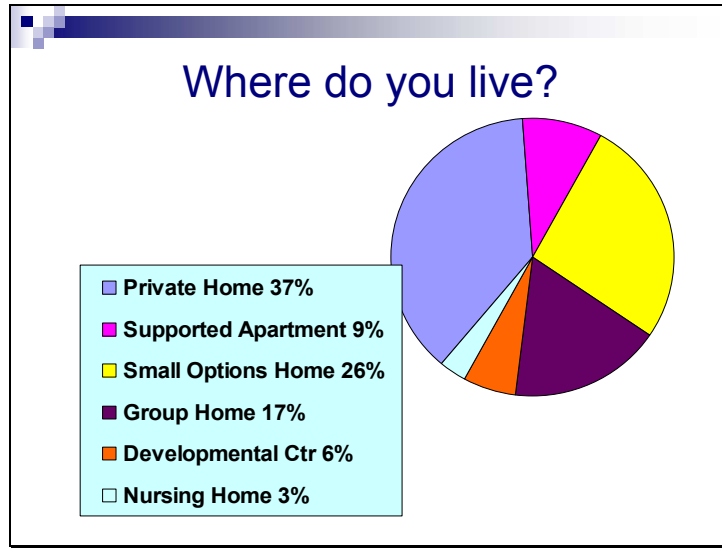
## Activities / Hobbies

■ 67% of individuals indicated that there was something stopping them from participating in the activities/hobbies that they like to do in their free time

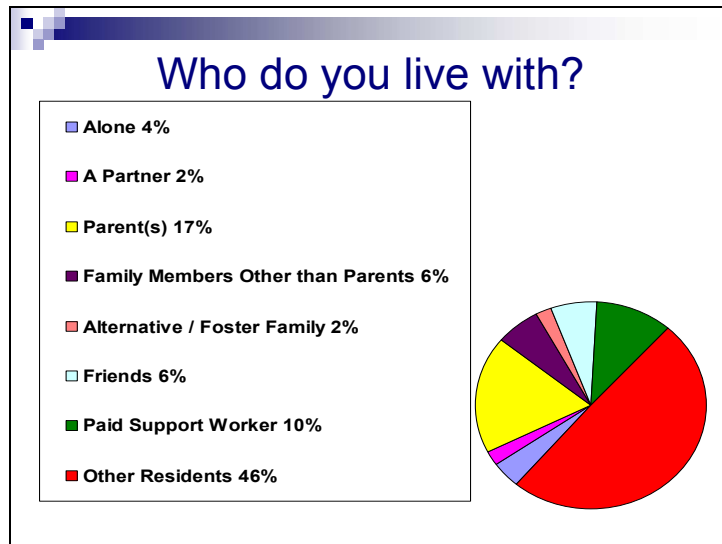
- Not enough money
- Transportation problems
- Not enough support
- Health concerns
- Physical challenges / barriers
- Responsibilities / Lack of time



Slide 19



Slide 20



## Where do you want to live?

- 50% of people said they are already in their home of choice
- Top living choices include:
  - At home with parent(s)
  - Private home or apartment
  - Private home or apartment with paid support
  - With a spouse, partner, friend, or sibling
  - Group / community home




## Diagnosis?

Yes 43%, most common diagnosis:

- Intellectual Disability
- Down's Syndrome
- Cerebral Palsy
- Spina bifida
- Autism

## How healthy do you feel?

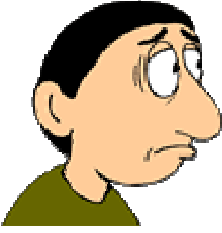
- Almost 78% of the people surveyed said that they feel healthy or very healthy.



- Some of the most common health concerns were: **diabetes, weight loss, and eating healthy**


## Health and Wellbeing

- How often do you feel anxious, nervous or worried?
  - A lot – 25%
  - Sometimes – 56%
  - Never – 17%




## Health and Wellbeing

- How often do you feel positive, optimistic, or upbeat?
  - A lot – 58%
  - Sometimes – 38%
  - Never – 3%



## Health and Wellbeing

- How often do you feel sad or depressed?
  - A lot – 11%
  - Sometimes – 64%
  - Never – 24%



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## Health and Wellbeing


How often do you worry about?

- Money** – A lot 31%; Sometimes 33%
- Family Responsibilities** – A lot 18%; Sometimes 32%
- Bullying** – A lot 17%; Sometimes 38%
- Discrimination** – A lot 14%; Sometimes 28%


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## Health and Wellbeing

- Most people (97%) said that they have a regular doctor
- 64% reported they were able to get an appointment quickly when needed
- 85% reported that the doctor's office was easy to access




Slide 29



## Health and Wellbeing

- 76% reported that they feel the doctor spends enough time with them
- 81% reported that they feel the doctor shows interest in their problems
- 91% reported that they feel their doctor and the staff at the doctor's office treats them with respect

Slide 30




## Health and Wellbeing

- Most common health services currently being used (highest to lowest):
  - Social Work / Care Coordinator
  - Vision Care (Eye Care)
  - Psychology / Psychiatry (Mental Health Services)
  - Home Care
  - Nutrition (Healthy Eating)

Slide 31

## Assistive Technologies

- Top 4 technologies currently being used:
  - Glasses
  - Cane or Walker
  - Manual Wheelchair
  - Positioning Equipment

A cartoon illustration of a person with dark hair and glasses, wearing a light-colored shirt, holding an open red book and reading it.


Slide 32

## Assistive Technologies

- Top 4 technologies that people think they may need in the future:
  - Cane or Walker
  - Glasses
  - Hearing aids
  - Magnifiers

## Future Directions

- Continuing survey in the Central Region of Nova Scotia with a special focus on reaching people who are not currently receiving services, the 'hidden population'.
- Full survey in Pictou County, Nova Scotia beginning September 2011.
- Province-wide survey



A map of Nova Scotia showing its counties. Pictou County, located in the central-eastern part of the province, is highlighted in red. The rest of the province is shown in a light grey color.

## Challenges

- Reaching 'hidden population'
- Finding funding to cover the costs of a province-wide survey
- Finding sustainable funding to manage an ongoing information system (data collection, storage, and management)

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**Thank You!**


Contact?

Office Phone: 457-6218

Email: [thepowerofknowing@msvu.ca](mailto:thepowerofknowing@msvu.ca)

Website: [www.msvu.ca/thepowerofknowing](http://www.msvu.ca/thepowerofknowing)

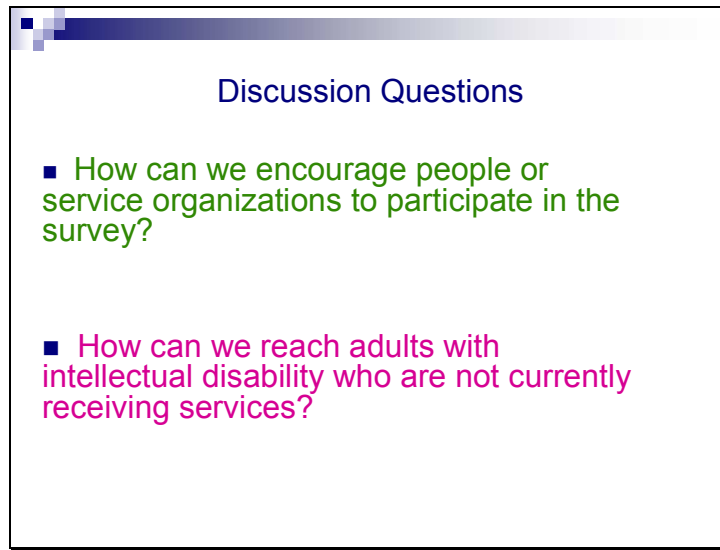
Slide 36



**Discussion Questions**

- In your opinion, what are the strengths and weaknesses of our survey process?
- What questions would you like answered regarding health and social service needs? & How would this information be useful to you?

Slide 37



Discussion Questions

- How can we encourage people or service organizations to participate in the survey?
- How can we reach adults with intellectual disability who are not currently receiving services?

Slide 38

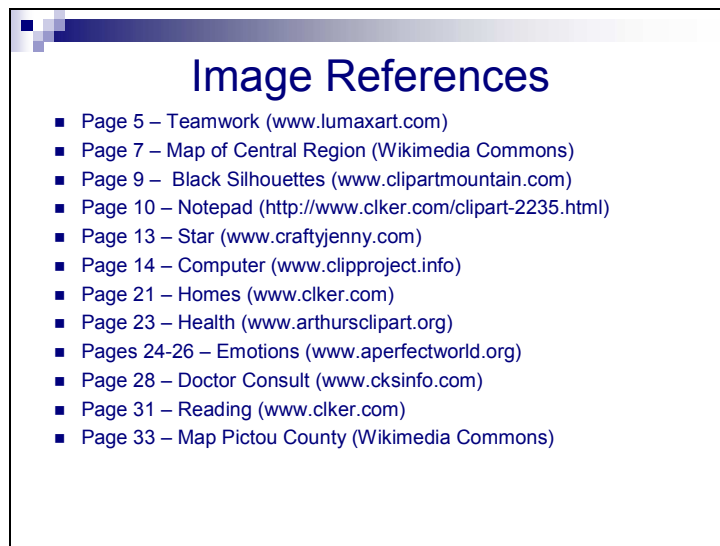


Image References

- Page 5 – Teamwork ([www.lumaxart.com](http://www.lumaxart.com))
- Page 7 – Map of Central Region (Wikimedia Commons)
- Page 9 – Black Silhouettes ([www.clipartmountain.com](http://www.clipartmountain.com))
- Page 10 – Notepad (<http://www.clker.com/clipart-2235.html>)
- Page 13 – Star ([www.craftyjenny.com](http://www.craftyjenny.com))
- Page 14 – Computer ([www.clipproject.info](http://www.clipproject.info))
- Page 21 – Homes ([www.clker.com](http://www.clker.com))
- Page 23 – Health ([www.arthursclipart.org](http://www.arthursclipart.org))
- Pages 24-26 – Emotions ([www.aperfectworld.org](http://www.aperfectworld.org))
- Page 28 – Doctor Consult ([www.cksinfo.com](http://www.cksinfo.com))
- Page 31 – Reading ([www.clker.com](http://www.clker.com))
- Page 33 – Map Pictou County (Wikimedia Commons)

## Appendix B – Workshop Agenda

### *Intellectual Disabilities Service Needs Research Alliance*

#### *Stakeholders' Workshop Agenda*

**Where:** Piers Military Community Centre, Windsor Park, Halifax, NS  
**When:** Thursday, October 15th 2009 10:00am to 2:30pm

<i>Time</i>	<i>Activity</i>
10:00 – 10:15	Welcome & Introduction
10:15 – 11:00	Presentation of Survey Results (to-date)
11:00 – 12:00	Small Group Discussions and Report Back
12:00 – 13:00	<b>Lunch Break</b>
13:00 – 13:45	Small Group Discussions and Report Back
13:45 – 14:00	Summary of lessons learned from small group discussions
14:00 – 14:15	Discussion of future directions for the project
14:15 – 14:30	Questions / Comments

Lunch and refreshment break will be provided, including coffee/tea and muffins upon arrival. If you have questions or would like more information about the Stakeholders' Workshop, please feel free to contact our project assistant:

Priscilla Frenette  
Phone: 457-6218  
Email: [thepowerofknowing@msvu.ca](mailto:thepowerofknowing@msvu.ca)



**IDSN**  
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Service Needs Research Alliance