



# **Building a database for children with disabilities using administrative data and surveys**

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# THE CANADIAN EXPERIENCE – BUILDING A NATIONAL DATABASE ON DISABILITY

1981 OBSTACLES report

1981 to present

- Consultation to identify what data are needed
- Consultation to determine what questions should be used to identify the population with disabilities

1986, 1991, 1996, 2001, 2006

- Adding questions on disability to the Census of Population

1983/84

- A follow-up to the monthly Labour Force Survey

1986, 1991, 2001, 2006

- Disability-specific surveys using the Census as the sampling frame

1991 to date

- Adding Census disability questions to ongoing social surveys

2009 to date

- Development of the new disability data strategy using existing surveys and administrative data

## FOR THE CEE/CIS REGION – WHAT DO YOU NEED TO KNOW BEFORE YOU START COLLECTING DATA TO SUPPORT THE INCLUSIVE EDUCATION INITIATIVE?

- **WHY** do you need the data?
- **WHAT** data are needed?
- **HOW** are children with disabilities currently identified?
- **WHO** can provide the data that is needed?
- **WHAT** vehicles can be used to collect the data?
- **WHAT** options are there to disseminate the data?

# WHY DO YOU NEED THE DATA?

With the goal of *inclusive* education for all children, I suggest that you need to know .....

- The current state of the education system
- The number of children with disabilities
- The accommodations that children with disabilities are receiving that improve their access to *inclusive* education
- The unmet needs of children with disabilities that prevent or impede their access to *inclusive* education

# WHAT DATA ARE NEEDED?

- Status of education system in the country
- Prevalence of disability
- Demographic characteristics of children with disabilities
- Level of education
- Barriers/accommodations –technical aid(s)/ human support, attitudinal, structural, economic

# HOW DO YOU IDENTIFY CHILDREN WITH DISABILITIES?

- Definition(s) of children with disabilities currently in each country
- Understanding of the definition of disability with the community
- CRPD (Article 1) '*.... those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*'.
- Working with what you have and what you know

## WHO CAN PROVIDE THE DATA THAT ARE NEEDED?

- Education infrastructure
  - Ministry of Education officials
- Information about children with disabilities
  - administrative files within Health, Social and Education Ministries
  - parents

# WHO CAN PROVIDE THE INFORMATION ABOUT THE EDUCATION INFRASTRUCTURE?

Education Ministry officials – structured interviews to obtain:

- status of education system (inclusive, integrated, special schools, mix)
- inventory of barriers/accommodations – ramps, transportation, sign language interpreters, technical aids, revised curriculum, other



# WHO CAN PROVIDE THE INFORMATION? – EDUCATION INFRASTRUCTURE

Education Ministry officials – structured interviews

- *Advantage of approach*

- provides assessment of “current” status that can be updated on a regular basis
- relatively inexpensive to undertake

- *Difficulties that may be encountered*

- availability of the information for all schools

# WHO CAN PROVIDE INFORMATION ABOUT CHILDREN WITH DISABILITIES?

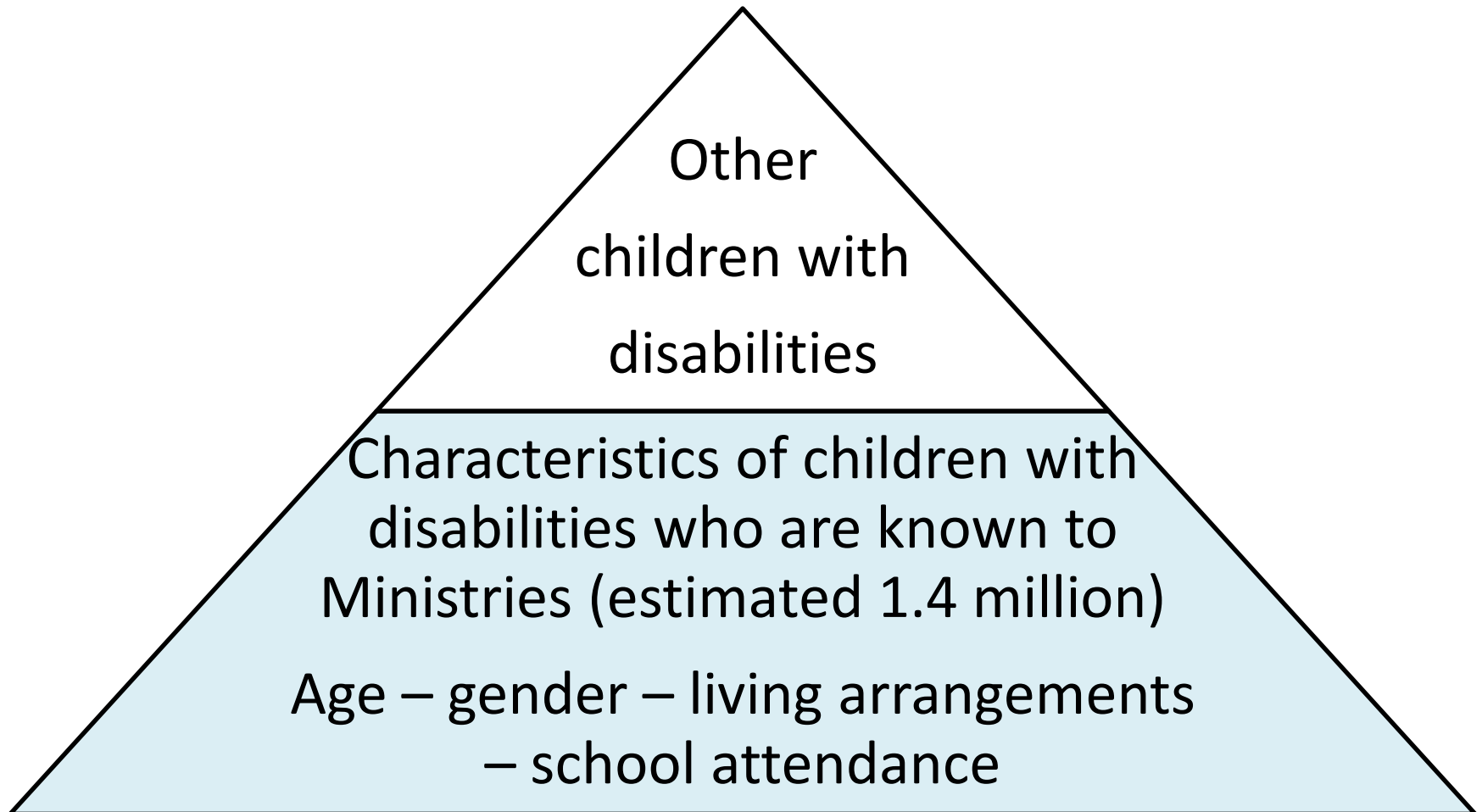
There is an *estimated* 2.5 million children with disabilities in the CEE/CIS region:

- an *estimated* 1.4 million have been identified by Health, Education or Social ministries.
- an *estimated* 1.1 million have yet to be identified.

# FOR THE CHILDREN WITH DISABILITIES WHO ARE ON MINISTRY REGISTERS ...

- Arrange for access to ministry files – Health, Education, Social
- Information to be collected from administrative files (if available):
  - date of birth
  - gender
  - nature of disability
  - other identifiers such as name of mother, name of father
  - living arrangements (i.e. - in institution, not in institution)
  - school attendance (i.e. – does not attend school, attends special school, attends regular school)
- Access software that can identify duplicates

# FOR CHILDREN WITH DISABILITIES - YOU COULD NOW PRODUCE



# FOR CHILDREN WITH DISABILITIES WHO ARE NOT ON MINISTRY LISTS

## Need to:

- gain support of parents
- change attitudes about self-identifying a child with a disability
- conduct a survey
  - post-censal survey
  - add disability questions to existing social survey

## A POST-CENSAL SURVEY ....

- is a survey that uses a census question or questions to identify a target population.
- is usually conducted shortly after a census using the census staff to select the sample and collect the data.
- is a cost-effective way to collect information about a rare population.
- augments the census data with information specific to the target population

# **TO CONDUCT A POST-CENSAL SURVEY OF CHILDREN WITH DISABILITIES, YOU NEED TO ....**

- design questions to identify the population with disabilities on your census questionnaire
- design a questionnaire that includes questions to obtain the data that you need to measure the extent of inclusive education in your country
- develop a sample design that will allow you to produce reliable data
- develop a processing system that captures and edits the data and links the post-censal data to the census data
- secure the funding to conduct, process and disseminate the data

# SOME EXAMPLES OF CENSUS DISABILITY QUESTIONS THAT HAVE BEEN USED FOR A POST-CENSAL SURVEY

## New Zealand

**16** Mark as many spaces as you need to answer this question.

Does a health problem or a condition you have (lasting 6 months or more) cause you difficulty with, or stop you from:

- seeing, even when wearing glasses or contact lenses
- hearing, even when using a hearing aid
- walking, lifting or bending
- using your hands to hold, grasp or use objects
- learning, concentrating or remembering
- communicating, mixing with others or socialising

or  no difficulty with any of these

**17** Do you have a long-term disability (lasting 6 months or more) that stops you from doing everyday things other people can do?

- yes
- no



# SOME EXAMPLES OF CENSUS DISABILITY QUESTIONS THAT HAVE BEEN USED FOR A POST-CENSAL SURVEY

## Ireland

### 15 Do you have any of the following long-lasting conditions?

- (a) Blindness, deafness or a severe vision or hearing impairment
- | Yes                        | No                         |
|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> |
- (b) A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying
- | Yes                        | No                         |
|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> |
- (c) A learning or intellectual disability
- | Yes                        | No                         |
|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> |
- (d) A psychological or emotional condition
- | Yes                        | No                         |
|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> |
- (e) Other, including any chronic illness
- | Yes                        | No                         |
|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> |

### 16 IF 'Yes', to any of the conditions specified in Question 15, do you have any difficulty in doing any of the following activities?

- (a) Learning, remembering or concentrating
- | Yes                        | No                         |
|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> |
- (b) Dressing, bathing or getting around inside the home
- | Yes                        | No                         |
|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> |
- (c) Going outside the home alone to shop or visit a doctor's surgery
- | Yes                        | No                         |
|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> |
- (d) Working at a job or business or attending school or college
- | Yes                        | No                         |
|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> |
- (e) Participating in other activities, for example leisure or using transport
- | Yes                        | No                         |
|----------------------------|----------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> |

# SOME EXAMPLES OF CENSUS DISABILITY QUESTIONS THAT HAVE BEEN USED FOR A POST-CENSAL SURVEY

## Canada

ACTIVITIES OF DAILY LIVING	07.	08.
<b>7</b> Does this person have any <b>difficulty</b> hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?	01 <input type="radio"/> Yes, sometimes 02 <input type="radio"/> Yes, often 03 <input type="radio"/> No	01 <input type="radio"/> Yes, sometimes 02 <input type="radio"/> Yes, often 03 <input type="radio"/> No
<b>8</b> Does a physical condition <b>or</b> mental condition <b>or</b> health problem <b>reduce the amount or the kind of activity</b> this person can do: (a) at home?	04 <input type="radio"/> Yes, sometimes 05 <input type="radio"/> Yes, often 06 <input type="radio"/> No	04 <input type="radio"/> Yes, sometimes 05 <input type="radio"/> Yes, often 06 <input type="radio"/> No
(b) at work or at school?	07 <input type="radio"/> Yes, sometimes 08 <input type="radio"/> Yes, often 09 <input type="radio"/> No 10 <input type="radio"/> Not applicable	07 <input type="radio"/> Yes, sometimes 08 <input type="radio"/> Yes, often 09 <input type="radio"/> No 10 <input type="radio"/> Not applicable
(c) in other activities, for example, transportation or leisure?	11 <input type="radio"/> Yes, sometimes 12 <input type="radio"/> Yes, often 13 <input type="radio"/> No	11 <input type="radio"/> Yes, sometimes 12 <input type="radio"/> Yes, often 13 <input type="radio"/> No

**FOR INFORMATION ONLY**

# **TO CONDUCT A POST-CENSAL SURVEY OF CHILDREN WITH DISABILITIES, YOU NEED TO ....**

- design questions to identify the population with disabilities on your census questionnaire
- design a questionnaire that includes questions to obtain the data that you need to measure the extent of inclusive education in your country
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# TWO SURVEY OPTIONS

	<b>Post-censal survey</b>	<b>Ongoing social survey</b>
Sample design	Using Census to locate rare population – efficient way to identify households that include children with disabilities	Sample design fixed
Sample size	Can determine sample required to produce reliable estimates	Sample size fixed so there may not be sufficient sample to accurately count children with disabilities
Number of questions	No limit plus access to Census data for disabled/non-disabled comparison	Usually are limited to a few questions
Cost	Significant – need to develop census disability questions, questionnaire, processing system and dissemination plan	Marginal cost only to add questions to existing questionnaire, modify processing system and develop dissemination plan

## **WHAT OPTIONS DO YOU HAVE TO DISSEMINATE THE DATA?**

You could:

- build an information platform
- develop indicators for UNCRDP and EFA
- develop indices such as a barriers and accommodation index to monitor progress of inclusion

# AN INFORMATION PLATFORM .....

- ... brings together sources that include:
  - administrative files;
  - censuses;
  - statistical surveys; and
  - qualitative initiatives.
- ... provides standardized documentation for all sources
- ... includes links to where the information can be found

# INDICATORS FOR UNCRPD – EFA - INCLUSION

Assuming:

- data have been collected from Ministries and households, and
- data are complete, i.e. – no significant under-coverage

You could generate:

- the prevalence rate of disability among children by age, gender, type of disability
- the proportion of children with disabilities who are attending school
- the proportion of children with disabilities who are attending school by age, gender, type of disability and type of school
- others???

# A BARRIERS AND ACCOMMODATION INDEX

Assuming:

- data have been collected from Ministries and households, and
- data are complete, i.e. – no significant under-coverage, and
- data were collected concerning barriers encountered and accommodations needed/received

You could:

- develop a barriers and accommodation index similar to the Adult BAI but relevant to children
- use the BAI to monitor social inclusion



## IN CONCLUSION .....

- not an easy task ahead of you and clearly, not one that you will accomplish quickly
- I suggest that it will be an iterative process that sometimes feels that you are taking three steps forward and then maybe two steps back
- I look forward to having ongoing discussion with you over the next few days – and
- picking up the dialogue during Session 14 on Thursday afternoon

THANK YOU!