

СОЗДАНИЕ БАЗ ДАННЫХ О ДЕТЯХ С ОГРАНИЧЕННЫМИ ВОЗМОЖНОСТЯМИ ЗДОРОВЬЯ, ИХ ИССЛЕДОВАНИЕ И ИСПОЛЬЗОВАНИЕ В КАНАДЕ

BUILDING DATABASES ON CHILDREN WITH DISABILITIES, THEIR ANALYSIS AND USE IN CANADA

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Аннотация

В данной статье авторы указывают, что консультационный центр Adele Furrie Consulting Inc. в течение 30 лет ведет работу по сбору баз данных о взрослых и детях с ограниченными возможностями здоровья, анализу этих данных и распространению данной информации заинтересованным учреждениям в Канаде. Авторы выделяют сущность и особенности барьеров, которые препятствуют интеграции лиц с ограниченными возможностями здоровья в выбранную ими сферу жизнедеятельности. Это может быть административный ресурс, родители, школа или университет. Авторами теоретически обоснована и выявлена необходимость совместного пополнения и использования базы данных детей с ОВЗ на основе опыта Канады, предложены задачи сбора данных о лицах с ограниченными возможностями здоровья и поэтапные методы их реализации.

Abstract

In this article, the authors share the experience of Adele Furrie Consulting Inc, the counseling center, which for 30 years has been working on the collection of databases on adults and children with disabilities, analyzing these data and disseminating this information to interested institutions in Canada. The authors identify the nature and characteristics of barriers that impede the integration of persons with disabilities into their chosen fields of life. These may be administrative resources, parents, school or university.

The authors theoretically prove and identify the need for joint replenishment and use of the database of children with HIA based on the experience of Canada, proposed task of collecting data on persons with disabilities and methods to implement them stage by stage.

Ключевые слова: интеграция обучения, дети с ограниченными возможностями здоровья (ОВЗ), барьеры интеграции обучения лиц с ОВЗ.

Key words: integration of education, children with disabilities, the barriers for integration of persons with disabilities.

Designing surveys, collecting data, analyzing the data and disseminating it have been the focus of my professional life since I was 16. However, it was not until I was asked to take responsibility for the new disability data portfolio at Statistics Canada that I truly realized the impact the statistically sound data could have on the lives of Canadians.

The development of a disability database that not only enabled prevalence rates by age and gender and type and severity of disability but, and it is very important, gave information on the nature and extent of the barriers encountered by adults and children with disabilities and their families that prevented or impeded their inclusion in their chosen life activities – be it school, work or play.

As part of their response to the UN Decade of the Disabled the Canadian government created a Special Parliamentary Committee comprised of federal politicians to cross the country to hear from Canadians with disabilities, their families, the NGO's and other levels of government. Their mandate was to gain an understanding of the issues facing Canadian children and adults with disabilities so that the government could begin a concentrated effort to remove barriers and improve the quality of life for Canadians with disabilities regardless of their age where they

lived, their ethnic origin. This consultation formed the basis for the ongoing dialogue that has continued to today. The development took time – almost 30 years – with each step building on the previous one.

The Committee's report, entitled «Obstacles», included 130 recommendations with one directed to Statistics Canada to develop and maintain a statistical database on disability. That's where I came in. I was asked to take on the responsibility to use whatever means were available to develop such a database. With the help of my team members and the financial support of the government and the support of the disability community we did just that. Questions to identify the population with disabilities were added to the long form of the Census of population – two questions to the 1986 – 1991 and 1996 Censuses and then those two questions were revised for the 2001 and 2006 Censuses.

We conducted a disability-specific add-on to our monthly Labour Force survey in October of '83 and June of '84.

We developed the post-censal survey methodology – that is we used the Census disability questions to identify the population with disabilities and then did a follow-up survey with a sample of people who had identified as having a disability and asked them about the accommodations they had received and the barriers that they encountered because of their disability. We conducted four of these surveys.

We also added the Census disability questions to other ongoing social surveys so we had multiple sources for data concerning children and adults with disabilities. Then in 2009 it was decided that there would be a shift in the focus for obtaining data about the impact of living with a disability. We are now exploiting administrative data and we are developing new questions to identify the population with disabilities and we will add those questions to ongoing social surveys. This change in direction came at the same time that Canada ratified the UN Convention on the Rights of People with Disabilities. As a member of the technical advisory committee for the development of this new approach I can tell you that while in the long run it may prove to be better than the old approach in the short run we are without up-to-date data and for me that is very disturbing.

In developing this new approach we asked ourselves six questions and I thought that I would do the same for this presentation. I will ask the same six questions and then outline for you some possible answers that reflect my knowledge of the situation in the CEE/CIS region.

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? Beginning with “Why do you need the data?” With the overall goal of inclusive education for all children – for children with disabilities – I suggest that you need to understand 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.

From my experience in Canada and in doing similar work in other countries, these are the data that could be collected and have as their focus education for all children with disabilities. 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.

Remember that not all data have to be collected at once and, as in Canada, you decide on a starting point and then move forward adding and changing as you go. I would suggest that a good starting point could be the status of the education system in the country with respect to children with disabilities maybe you already know this and after that the prevalence of disability by nature and severity and by age and gender and then information about school attendance –

grade level, type of school and type of class in school. If you are able to get those data then you would have a great start with data that would

facilitate development of some of the indicators that you need to respond to Article 24.2 and Article 33 of the UNCRPD and also for the EFA. How do you identify children with disabilities? This is by far the most challenging of the six questions and the one that most countries and also international initiatives are struggling with. As I see it you have three starting points: what are the definitions that are currently being used in your country, what is the common understanding of the definition of disability in the community and the UNCRPD definition that starts with impairments to identify a group of individuals and then focuses on barriers that prevent or impede full and effective participation in their community.

The challenge is working with what you have and what you know. That was the situation in Canada when I took over the disability data portfolio. We consulted with parents, paediatricians, program managers who were offering services in support of children with disabilities and asked them what their definition of disability was. What we found was some similarity among the parties – all defined disability in the context of a health problem or condition with parents insisting that identifying children with disabilities should be only the first step. The second and more important step was to identify the barriers that they faced at school and in their community that prevented or impeded their participation.

We consulted with the international community and found that there was little work being done to develop questions for use in surveys that would identify children with disabilities. We got help from the international community with respect to questions to identify adults with physical and sensory disabilities but little with respect to mental, intellectual or learning disabilities. In fact, the international community is just now turning to questions to identify disability in children. The International Classification of Functioning, Disability and Health, the ICF for Children and Youth was published in 2007 and provides an excellent framework from which to develop questions to use in surveys and Censuses. The Washington Group established a working group in 2009 to develop questions for children and youth that embrace the framework provided in the ICF.

So you have an idea of why the data are needed, what data are needed and some of the issues concerning defining children with disabilities. The next question relates to who can provide that information. We suppose that Ministry of education officials, administrative files within Health, Social and Education Ministries, parents can provide this information. According to information obtained from UNICEF I understand that there is an estimated 2.5 million children with disabilities in your region. Of those an estimated 1.4 million have been identified by at least one of Health, Education or Social ministries. That leaves just over one million children with disabilities who have yet to be identified.

I don't know what information these ministries have about these identified children with disabilities but let's assume that each of the ministries have some data such as arrange for access to ministry files, information to be collected from administrative files (date of birth, gender, nature of disability, other identifiers such as name of mother, name of father, living arrangements, school attendance), access software that can identify duplicates and they are willing to share those data. If that assumption is correct, then what needs to be done is to match the three files using software that has been created for this purpose and create one register that brings together the data for the child from all sources.

Record linkage is an integral part of the work that is done at Statistics Canada, we have never used it for a disability application but I came across an interesting article in the Journal on Developmental Disabilities from 2009 where researchers linked data from various administrative files to come up with an estimate of developmental disability in Manitoba – one of Canada's western provinces.

So, assuming that access is given and the files from the three ministries can be merged you could now produce characteristics of the estimated 1.4 million children. Information such as age, gender, whether the child lives in an institution and for those who do not – information about

school attendance. But what of the estimated 1.1 million who are not on any registry. This is the most difficult population to find and to get information about. The difficulty comes from how society views disability and convincing parents that there is no stigma attached to having a child that has difficulty learning or has difficulty seeing or has attention difficulties and so on.

Without the support of parents, then trying to conduct a survey regardless of what type of survey – would be all for naught. But let's assume that we can through positive messages begin to see a change in attitudes towards disability. You could then look at two options for conducting a survey – adding disability questions to an existing social survey or conducting a post-censal survey.

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

What do you need to do in order to be able to conduct such a survey? 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.

Three countries have used the post-censal methodology to collect data on their child and adult population with disabilities. New Zealand's census disability questions have evolved over time. Questions attempt to remove any persons who might have temporary limitation in activity by introducing duration of six months or more.

Ireland's disability questions in their 2006 Census separated condition from limitation.

Canada's questions are less detailed. Questions deal with difficulty across a number of activities, a more general approach but then introduce a measure of severity asking the respondent to indicate «sometimes» or «often». Then asks about reduction in activity or change in the kind of activity and gives the contexts – home, work or school and in other activities.

Assuming that you were able to secure the funding for a survey, here are some options that you could consider 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.

I strongly support the development of an information platform because it provides a single portal to all information available on one subject. I am very impressed with the usability of the Irish stats office. Called StatCentral – you can click on a topic and it brings you to what information is available on the topic and where you can find it. I am encouraging Canada to follow this model because data sources can be diverse and knowing that the source exists is one thing but knowing where to find it is another.

Assuming that you started your data collection activities asking only about type of disability, some demographic characteristics and information about level and type of education and assuming that you were able to collect these data from Ministry files and households and assuming that you believe that there is no significant under-coverage, then you could generate some indicators for the UNCRPD and Equality for All, such as: the prevalence rate of disability among children by age, gender, type of disability; the pronunciation 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. There may be others but what a great start!

But suppose you went one step further and collected information on the barriers encountered and accommodations that were received or needed, you could then create a barriers and accommodation index similar to the one that I developed with a research team for a literacy and disability project in 2003 for adults with disabilities. This index used data from the 1986 post-censal survey and looked at barriers and accommodations across all of the domains of daily

living. It was a fascinating exercise using the human rights model of disability – so applicable for use in monitoring social inclusion and the UNCRPD. You could develop a similar index for children.

So in conclusion I would like to say that it is 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. But it is a good start, do not be afraid of changes. Good luck!

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