

Disability Monitor Initiative Journal for South East Europe

The focus of this issue:

Disability Statistics Fight Invisibility



Disability pension fund in Serbia is a source of data on disability

In many countries across the globe statistics on disability are insufficient and poorly developed or, in many cases, they are non-existent. In many countries in South East Europe official statistics on disability are practically absent. This is one of the reasons HI-SEE initiated a preliminary assessment of disability and statistics in Albania, Bosnia and Herzegovina and Serbia. In fact, in Albania, Bosnia and Herzegovina and Serbia, there are no official statistics on the number of people with disabilities and in none of the countries is disability included in national censuses. The lack of comprehensive and up-to-date statistical information on disability contributes to the exclusion of disability from the political agenda and makes it very challenging to build effective reforms around this issue.

The activists from the disability movement in the region consistently stress the importance of disability statistics, in order to end this marginalization and to have a more accurate picture of the situation in which people with disabilities live. Comprehensively collected, statistical information will help better target the issues affecting the lives of people with disabilities on a daily basis, such as discrimination and poverty. This is crucial for developing comprehensive policies and for monitoring their implementation. The statistical data can also be used to measure how the situation improves over time.

continued on page 2

Inside you can find:

POINTS TO CONSIDER BY GERTA PICARI

*Director of Instat-State Institute
for Statistics of Albania*

CONDUCTING RESEARCH,
*Interview with Marija Dragovic,
project assistant, Association
of Students with Disabilities of
Serbia*

THE DEVELOPMENT OF DISABILITY STATISTICS Experience in Honduras

*by Thierry Gontier, International
disability statistics expert*

The HI-SEE team would like to wish you all a happy and successful 2007 and congratulate everyone on the adoption of the International Convention on the Rights of People with Disabilities!

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Continued from the front page...

Collecting statistics on people with disabilities is not something new. It is each **state's responsibility to collect information** on the general population and this includes people with disabilities. Statistics should show not only the number of people with disabilities living in a given country but **data should show their living conditions** as well, including income levels, types of housing, access to services, level of education and employment records. It is also important to have **statistics that compare people with disabilities with people without disabilities** as this provides an overview of indirect levels of discrimination, such as the education levels of people with disabilities versus those of people without disabilities.

It is with these priorities and recognition of the clear need for disability statistics in the region that Handicap International South East Europe initiated an assessment of the situation in Albania, Bosnia and Herzegovina and Serbia. Crucial in that assessment was a series of meetings with key actors involved in data collection in each country. Through these interviews, the HI SEE team formed an overview of the existing data, the prevailing trends and the roles of different stakeholders in data collection. A working paper with the findings of the assessment will be issued in February 2007 followed by local workshops gathering key stakeholders.

INTERNATIONAL FRAMEWORK ON DISABILITY AND STATISTICS

Both the UN Standard Rules and the UN Convention on the Rights of Persons with Disabilities outline the importance of disability statistics and set guidelines for collecting comprehensive data on a national level. **Each of these documents points to the state's responsibility to collect statistics on disability and involve people with disabilities in the processes of data collection and dissemination of information and in the analysis of the findings.**

The UN Convention on the Rights of People with Disabilities, Article 31 – Statistics and Data Collection

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:
 - (a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
 - (b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles of statistics.
2. The information collected in accordance with this article shall be disaggregated as appropriate and used to help assess the implementation of States Parties obligations under the present Convention, and to identify and address the barriers faced by persons with disabilities in exercising their rights.
3. States Parties shall assume the responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities Rule 13 - Information and research

States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities.

- States should, at regular intervals, collect gender-specific statistics and other information concerning the living conditions of persons with disabilities. Such data collection could be conducted in conjunction with national censuses and household surveys and could be undertaken in close collaboration, inter alia, with universities, research institutes and organizations of persons with disabilities. The data collection should include questions on programmes and services and their use.
- States should consider establishing a data bank on disability, which would include statistics on available services and programmes as well as on the different groups of persons with disabilities. They should bear in mind the need to protect individual privacy and personal integrity.
- States should initiate and support programmes of research on social, economic and participation issues that affect the lives of persons with disabilities and their families. Such research should include studies on the causes, types and frequencies of disabilities, the availability and efficacy of existing programmes and the need for development and evaluation of services and support measures.
- States should develop and adopt terminology and criteria for the conduct of national surveys, in cooperation with organizations of persons with disabilities.
- States should facilitate the participation of persons with disabilities in data collection and research. To undertake such research States should particularly encourage the recruitment of qualified persons with disabilities.
- States should support the exchange of research findings and experiences.
- States should take measures to disseminate information and knowledge on disability to all political and administration levels within national, regional and local spheres.

At the international level, there is an on-going debate to develop standards on the measurement of disability in population-based surveys known as the **Washington Group**. The Washington Group aims to guide the development of a small set or sets of general disability measures suitable for use in censuses, sample-based national surveys, or other statistical formats for the primary purpose of **informing policy on the equalisation of opportunities**.

Finally, the OSCE promotes the design of **evidence-based policies** which requires statistics in order to formulate the policies. The monitoring of these national policies, as well as the monitoring of the International Convention on the Rights of Persons with Disabilities will also require the construction of a new set of indicators on disability.

The Washington Group on Disability Statistics

The Washington Group (WG) on Disability Statistics was formed as a result of the UN International Seminar on Measurement of Disability in New York, June 2001. Among the main outcomes of that meeting was the recognition that statistical and methodological work was needed at an international level in order to **compare data on disability cross-nationally**. Thus, the UN Statistical Division authorized the formation of a City Group to address these issues. Since February 2002, the Washington Group has been operating under the aegis of the United Nations Statistical Commission and it meets once a year, gathering representatives of national statistics institutes, international agencies and non-governmental organisations.

The main purpose of the Washington Group is the promotion and coordination of international cooperation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys which will provide basic necessary information on disability throughout the world. More specifically, the Washington Group aims to guide the **development of a small set or sets of general disability measures (or questions)**, suitable for use in censuses, sample based national surveys, or other statistical formats, for the primary purpose of informing policy and policy-makers on equalization of opportunities.

The second priority of the Washington Group is to recommend one or more **extended sets of questions** for surveys to measure disability, or principles for their design, to be used as components of population surveys or as supplements to specialty surveys such as Living Standards Measurements Surveys (LSMS), Household Budget Surveys (HBS) or Labour Force Surveys (LFS).

At the last meeting in Rio de Janeiro in 2005, the Washington Group identified three major categories of purposes for statistical data collection on disability: 1) service provision, 2) monitoring functioning in the population and 3) assessment of equalisation of opportunities.

Equalisation of opportunities was identified as feasible and relevant for all countries in the proceses of policy making. This issue was then selected as a primary concern and the key purpose for the development of an **internationally comparable general disability measure. This disability measure is based on adding questions to national censuses on disability and the WG developed a draft set of 6 questions for this purpose** to identify all those at greater risk than the general population as result of limitations in activity or participation. The ICF was used as the conceptual starting point for formulating these questions.

The questions are intended for use primarily in national census formats and can be used for **international comparison** of the resulting data. In the latter, the objective would be to identify persons with similar types and levels of limitations in basic activity functioning regardless of nationality or culture.

The intended use of this data would be to compare levels of participation in employment, education, or family life for those with a disability versus those without to see if persons with disabilities have achieved social inclusion. In addition, the data could be used to monitor prevailing functioning trends for persons with limitations in the particular basic activity domains.

Pertinent to the formulation of these questions is the definition for statistics purposes which is an on-going debate within the WG.

On the European level, the EU statistical office, EUROSTAT has developed different tools with a standardized methodology producing comparable information for Member States of the European Union, with 3 general disability/health items and questions. They have also composed a draft list of 30 specific core items for the measurement of disability in European population surveys which correspond to the priorities established within the Washington Group.



Disability advocates at work on the drafting of the Convention on the rights of persons with disabilities

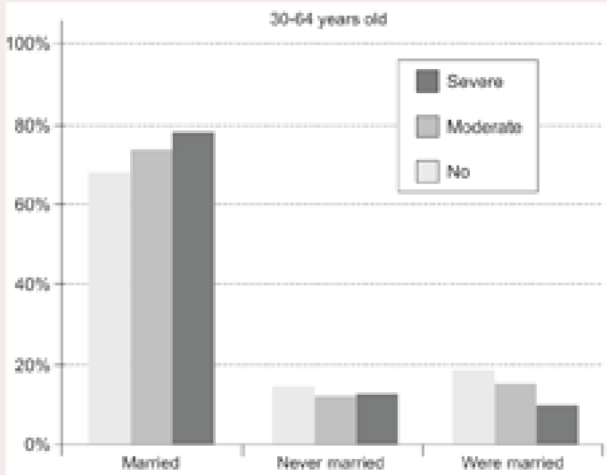
Statistics on the social participation of people with disabilities from the EU

EUROSTAT conducted a survey in 2001 called Disability and social participation in Europe which responded to the growing demand for internationally comparable statistics on the situation of people with disabilities. This study also corresponded to the European Council resolution on equal opportunities for people with disabilities calling for more reliable statistics on people with disabilities to monitor their employment on the basis of comparable data. Similarly, data on the social inclusion of people with disabilities was required to guide the European Commission in 2003, the European Year of People with Disabilities. The survey was carried out by the EUROSTAT Health and Safety unit with support from the Directorate General for Employment and Social Affairs, Integration of People with Disabilities unit.

The survey attempted to answer the question, what is the degree of social participation of people with disabilities in Europe in the main areas of life including marriage, education, work, family and social contacts? The study tries to answer these questions using data from the European Community Household Panel (ECHP) covering many aspects of daily life including employment, income, demographic characteristics, the environment, health and education. The ECHP sample covers some

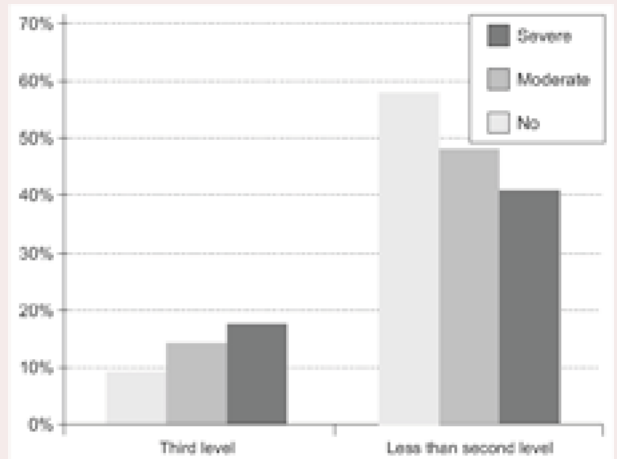
60,000 households and covers 14 out of 15 EU countries (Sweden was not included).

What the survey shows is a systematic difference between disabled and non-disabled populations in almost all areas of life. The magnitude of these differences varies from one country to another and the differences in educational, social, health and

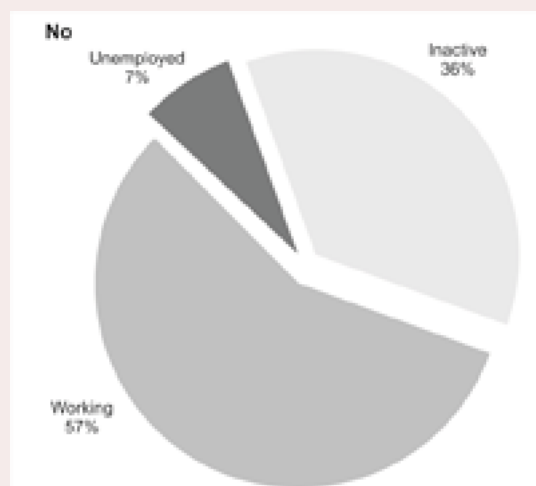
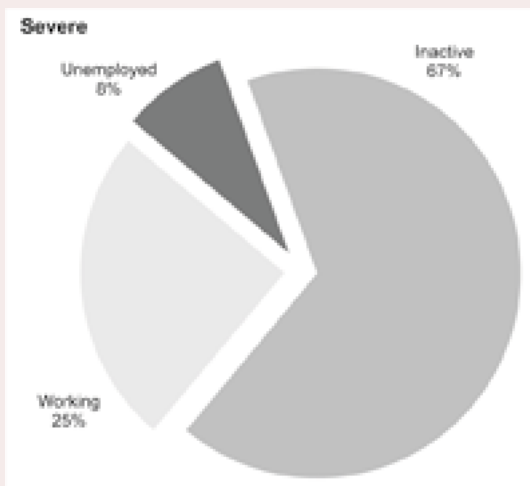


pension systems make the data difficult to compare at times. For instance, on the question of marital status, people without a disability are more likely to marry (78%) than those reporting a moderate disability (73%) or a severe disability (67%).

In the field of education, people with disabilities are much more likely not to complete tertiary education or the third level of education than those without disabilities.



The percentage of inactive working age people with disabilities is significantly higher than people without disabilities, particularly for those with severe disabilities (67% vs. 36%). Only 25% of people with severe disabilities are employed compared to 57% of the population without disabilities.



These are just a few examples of the information that can be obtained from this survey but it is an important first step in having data with indicators on the social participation of people with disabilities. This kind of data can be used to guide policy-making on a European level and is a model for other countries in their efforts to implement policies on equal opportunities and full participation.

Source: EUROSTAT, Disability and Social Participation in Europe, 2001.

A BASIC GUIDE TO STATISTICAL DATA COLLECTION

Definition of Disability

Statistics are based on a set of statistical indicators that are designed to measure a specific issue. Critical to the design of statistical indicators is the definition of disability. In the region, the definition of disability is mainly based on the medical model. This means that the definition has a narrow scope, i.e. it is restrictive and exclusionary, leaving out whole segments of population with particular disabilities such as people with intellectual disabilities. Furthermore, the definition can often be contradictory depending on the different laws in which it is specifically defined. For example, in Albania, the National Disability Strategy gives a wide definition of disability but the specific laws on the status of people with disabilities are very narrow and do not include people with intellectual or psycho-social disabilities.

Depending on the choice of definition, statistics will cover a wide or a narrow group of people and this greatly impacts the data sets and the analysis of information. For example, according to the UN Compendium of Disability Statistics (DISTAT) compiled in 1992, the percentage of people who are disabled **ranges from 0.2 to as far as 20.9 % of the total population** in different countries under survey. A large part of this variation is due to the choice of definition of disability.

Methods for Collecting Data

A country can collect data on disability using three national data collection systems: **surveys, population censuses and registries (or administrative records)**.

1. Surveys

Sample surveys are not intended to enumerate and poll every household or individual in the country. They are designed to be representative of specific portion of population under study so they could be as small as 500 households or as large as 15,000. Surveys should be determined randomly to be representative of the population.

Surveys can be used to collect data on disability either by conducting a special survey on disability or by including questions or a module (a set of questions) on disability in another survey such as Labour Force Surveys, Household Budget Surveys or Living Standards Measurement Surveys.

Surveys cover many different and often specialized topics such as health, welfare, labour force, agriculture and other socioeconomic issues often through a series of detailed questions. The majority of surveys are household-based.

However, in surveys of the population with disabilities it is also important to include the general population for comparative purposes.

2. Population censuses

In most national statistical systems, population censuses are the principal source of statistical data on the population and its characteristics. A census is a nationwide study with every person enumerated separately and their characteristics recorded separately.

Universal enumeration, an essential feature, permits population censuses to provide comprehensive demographic, economic and social data for small geographical areas, which would not be possible with a sample survey. A population census is a complex and costly undertaking that the majority of countries are able to conduct at ten-year intervals only.

Using the census to collect information about a certain segment of the population is not a new concept, although census organizers typically try to avoid using the census to collect anything other than basic demographic information. However, with the high cost of data collection and the increasing need for socio-economic and demographic information, many countries are exploring the census as a way to obtain other types of data.

Although a broad range of topics can be included in a census, most can be covered only briefly because of budgetary, personnel and time constraints.

Disability is increasingly a topic investigated in a population census. For the first time, **the United Nations Principles and Recommendations for Population and Housing Censuses, Revision 1, includes disability as a topic that may be covered in censuses**.

3. Administrative records and registers

Information on disability can also be collected in administrative recording and registration systems. These include population registers, disability pension registration systems, social security systems, registries of occupational injuries, employment registries, rehabilitation programmes and other services for persons with disabilities. Usually the information in these systems has been collected for reasons other than statistical and is usually related to the administration of a particular programme or service for persons with disabilities who meet its specific criteria.

Registries can be restrictive sources of data firstly because there may be legal problems, such as privacy issues or confidentiality of personal information, in the use of administrative service records or registers for statistical purposes other than in support of the programme or service. Secondly, they only show the people with disabilities who have access to a particular programme or service. Thirdly, in many cases, the data in registries overlap or have duplicate information that cannot be disaggregated. However, in some cases, these barriers can be overcome and, particularly in conjunction with other data sources, administrative records can enrich our knowledge about trends concerning persons with disability.

THE SITUATION IN SOUTH EAST EUROPE: TRENDS, ACTORS AND STATISTICAL CULTURE

The findings of the HI SEE preliminary assessment show that existing disability data is often conflicting or contradictory, depending on the different sources, making it difficult to get an accurate picture of the situation. Also, they are generally framed in the medical model so that they are disaggregated by type of impairment. The information is mainly based on medical indicators such as the number of people in institutions or the number of people with a specific disability (e.g. paraplegic). More useful information for inclusive policy-making, such as the number of people with disabilities attending mainstream schools or the percentage of those employed in the open labour market, is almost impossible to find and when they do exist, they are not up-dated regularly.

Albania, Bosnia and Serbia have some general common patterns:

- Disability definitions are restrictive and exclusionary. They are also often contradictory, depending on different laws,
- The information collected does not capture the actual living conditions of people with disabilities,
- The data collection system is oriented towards use of registers to track beneficiaries of the social protection system,
- The population of people with disabilities covered by the registries is not complete: there is no information on people with disabilities who do not have access to services or who are not beneficiaries of social protection or disability pension. As a rule, the data on children with disabilities are often missing,
- Duplication of data is frequent. For instance, data on disability allowances and on access to institutions is duplicated and therefore cannot be aggregated,
- Even the surveys on disability that have conducted in the region are put to little or no use,
- Statistical culture in Serbia and Bosnia is underdeveloped, especially on socio-economic indicators,
- The ministries responsible for the coordination of disability issues are those of Labour, Employment and/or Social Affairs,
- Other services such as Health and Education do not usually have disaggregated data on access to mainstream services,
- Information on access of people with disabilities to mainstream services does not exist (with the exception of data collected by national employment bureaus in all countries and the Health Insurance Fund in Albania),
- None of the 3 states has any information on the coverage of services as they just have information on service users,
- Central Statistics Offices (CSOs) do not collect information on disability but are willing to do it.



A woman with autism working as an artist in Albania

The myth of the data base on people with disabilities

In all of the countries, many stakeholders discussed the need to create a unique database on individuals with disabilities within the responsible ministries as a way of developing statistical information. This is not a viable solution since a database on individuals cannot be used as a source of statistical information due to legislation protecting the privacy of individuals. On the EU level, there is strict legislation protecting the privacy of the individual (*REGULATION (EC) No 45/2001 on the protection of privacy of the individual with regard to the processing of personal data by the Community institutions and bodies and on the free movement of such data*) forbidding the circulation of data on an individual. These same standards will eventually be adopted in the region as part of the accession process.

Furthermore, ministries do not have the capacities and the know how of a Central Statistics Office to collect and aggregate the data. Therefore, it is more relevant to leverage the knowledge of CSO in order to have data on disability.

As outlined in the UN Standard Rules, a databank or database on disability (not persons with disabilities) should be developed to track the services available as well as include statistics on available services and programmes. The database should also include information on the different groups of persons with disabilities, such as DPOs. As is says in the UN Standard Rules: *They (States) should bear in mind the need to protect individual privacy and personal integrity.*

Different initiatives in each country

Bosnia and Herzegovina conducted a Living Standards Measurement Survey (LSMS) which included a question on disability in 2001 to 2005, an initiative driven by the World Bank. However, according to the Central Statistics Office, almost no national authority requested the results of the survey or used the data in policy-making. Furthermore, no DPOs were involved in the process so there was an overall lack of ownership on the project resulting in a lack of awareness about the survey from DPOs (with the exception of IC Lotos from Tuzla who was involved at the end of the project). Subsequently, the data is not being used by the disability community for analysis and lobbying. The LSMS will not be continued in 2007. However, a Labour Force Survey (LFS) and Household Budget Survey (HBS) are planned and there is a possibility to include disability in these surveys in 2008.

Albania has a more advanced statistical culture and the statistics methodology used by the CSO is closer to EUROSTAT standards. This implies that the Albanian CSO has a strong capacity to collect data on disability on a national level which should be leveraged by the state. There is also a National Disability Strategy in place in Albania that was adopted in 2004, but the implementation and monitoring of the Strategy has not fully begun and there are no monitoring indicators developed yet. Having a national disability strategy requires statistical data for monitoring implementation and this can be done by the CSO who has the capacity to do so.

In **Serbia**, an LSMS will be conducted as World Bank initiative and it is planned to include questions on disability thanks to the lobbying of DPOs and Handicap International. It will be important that DPOs and national authorities are involved in the process. A National Disability Strategy is currently being drafted and the Poverty Reduction Strategy Paper (PRSP) for Serbia includes a section on disability. Both documents present an excellent opportunity for creating statistical indicators to monitor the implementation processes. The Ministry of Labour, Employment and Social Affairs is currently conducting an assessment of institutional capacities to collect data on disability. This is another interesting opportunity for the advancement of the debate on disability statistics and it is important that DPOs are involved in the process.

To calculate these new social policy indicators such as increase in employment of people with disabilities in the open labour force or a higher percentage of people with disabilities completing higher education, the three countries will have to consider a different approach to collecting information on disability, and surveys will need to be implemented to collect the missing information.

ACTORS IN THE REGION

Central Statistics Offices

In all three countries, the Central Statistics Offices are in charge of national official statistics system. However, in Serbia and Bosnia and Herzegovina, the collection of some statistical information is delegated to other national institutions as it says in the Law on Statistics of Republic of Serbia, in Article 3: "Statistical surveys within the scope of their charge are organized and executed by other government authorities" and the Republic Fund for Pension and Disablement Insurance is one of the organizations expressly mentioned.

In all of the countries, CSOs are open and willing to work on disability statistics and have strong interests in this area. Nevertheless, for the moment they have very limited experience in this area. They have never conducted any census including questions on disability and never conducted surveys with a disability module or disability question with the exception of the Living Standards Measurement Survey (LSMS) in BiH.

Each CSO has a department or sector dedicated to demographic and social indicators with focuses on vulnerable populations but at this point they do not include disability. Nevertheless, these departments all have sufficient capacities to develop indicators on disability and to run in-depth surveys on this population.

Points to consider by Gerta Picari, the Director of Instat-State Institute for Statistics in Albania

When asked if Instat produces statistics on disability, Gerta Picari, the Director of Instat, explained that they collect data from the Ministry of Social Affairs on disability but as an institution, they do not produce statistics on this population. However, she explained that they are aware of the importance of this issue and are eager and willing to develop disability measurements. In fact, she said that was approached by a local DPO, Albanian Disability Rights Foundation (ADRF) to discuss these issues.

Ms. Picari was also well aware of the fact that it is the state's responsibility to collect information on the population. As she explained, Article 6 of the Law on Statistics of Albania, clearly states that the statistics system is: "...covering economic, social and environmental situation of the country and should focus on phenomena which are essential for decision makers and respecting citizens' right to information". However, she underlined that they cannot work on the issue until the government asks for the indicators to be developed. She also explained that in general, there is a weak statistical culture for users of data in Albania and this is a problem that needs to be addressed.

The director also explained that a Labour Force Survey will be carried out in 2007 and they would be open to including a question on disability. She also said that they are currently developing a 5 year strategy and they have asked all line ministries to submit to their requests for data.

While in Albania, HI discussed with different actors within the Ministry of Labour and Equal Opportunities about using this opportunity to submit a request for data on disability linked to the National Disability Strategy monitoring. However, it was clear that there is a lack of awareness on the need for indicators for monitoring the implementation of the strategy.

In the three countries the potential of the national statistical offices are largely underestimated or even ignored by the stakeholders of the disability sector. Central Statistical Offices (CSOs) are perceived as the place where technicians from the various ministries have to send their data from their registries. The CSOs are not generally seen as a source of new statistical information outside of the administrative registries.

Disabled People's Organisations (DPOs)

The DPOs in the three countries have contrasted awareness on the importance of disability statistics. The largest membership-based DPOs usually have registries of their members. They can find in their registers the basic information they need for lobbying

(education level, employment background, type of disability, age and gender) and in general, they do not pay major attention to other groups.

Smaller DPOs generally representing less protected groups or cross-disability organisations have shown more interest in these debates either because they are fighting for more visibility and recognition by authorities or because they are more familiar with making comparisons not only between the different groups of persons with disabilities but also between people with disabilities and the rest of the population.

In terms of statistics, DPOs are usually looking for basic statistics such as the prevalence of disability (i.e. the percentage of the population with disabilities) or data on the number of people with a specific impairment. They are interested in information giving a description of the population with disabilities but data on access to services, education, employment and healthcare was mentioned less frequently by DPOs.

For DPOs in the region the definition of disability is a sensitive issue. It is seen as a key issue as it underlies the population benefiting from social protection. Cross-disability organizations appear generally more open than others to the use of broad definitions of disability. Clearly there is a lack of consensus in the three countries between the DPOs, on the definition of disability.

There are several good examples in the region of DPOs who are beginning to conduct surveys and widen the perspective on disability data collection. One of the strongest examples is the Association of Students with Disabilities of Serbia.



Day Care Center in Albania

Conducting Research: interview with Marija Dragovic, Project Assistant, Association of Students with Disabilities (ADS) Belgrade

The Association of Students with Disabilities (ADS) of Serbia network has a good amount of experience in conducting research as they have either given or worked as a partner in three surveys¹ on disability. The first one was in 2003 on the promotion of inclusive higher education in Southeast Europe. The second one, “Disability is a matter of Human Rights” was conducted from November 2005 to February 2006. The last survey, up to this interview, was named “Promotion of Inclusive Education in Serbia and Montenegro”, looking at individual experiences related to the discrimination of people with disabilities, conducted from May to June 2006. In their “surveys“, ADS used a wide definition of disability, which also includes people with chronic medical problems.

This last “survey“ was conducted amongst the population with disabilities and had a sample of 545 people covering 15 municipalities in Serbia and 12 in Montenegro. The questionnaire contained both multiple-choice questions and those that people could answer themselves and it consisted of 5 different parts, each covering a different area of interest.

What was the need behind the research on discrimination?

This research was conducted before the anti-discrimination law on disability was passed. As a part of the Coalition against Discrimination who regularly submitted proposals to the committee drafting the law, ADS was well aware of the issue but the general population was definitely not and our research reflected this. Yet, at that time our specific reason for carrying out this kind of “survey“ was to see if and how we should offer legal aid services to people with disabilities, to see if they were ready to use it. So, one of the aims of the survey was to see how to design legal aid services. We are still working with the results we collected, analyzing them, in order to develop this kind of service.

How did the implementation go?

There were 14 people who administered the “survey“ throughout the municipalities in Serbia and Montenegro. We wanted to include all the actors involved in problem of discrimination; line ministries, institutions and city services, but we ended up conducting it in cooperation with centers for social welfare, the Ministry of Human and Minority Rights and the People’s Office. The common reply from the other stakeholders was that people with disabilities were not under their jurisdiction.

In terms of timing, it took us a long time to formulate the questionnaire, more than a month in total. The time it took to get answers from the participants varied but the topic of discrimination can be very personal and people have lots of bottled up emotions so they often have a need to speak at some length.

Once we had the responses from all survey takers, we had to begin the data analysis process. A psychology student assisted us in the analysis of the data as he had experience in conducting surveys. He also helped to teach us how to use SPSS, a statistics computer program for analyzing data.

Which results would you stress?

The understanding of discrimination varies widely amongst people. Some people with disabilities even thought that discrimination meant not receiving the benefits they were entitled to; others understood it as being insulted on the grounds of their disability by a person without one. There were also those who defined discrimination as ungrounded changes in a

person's behavior towards a person with disabilities

It is also striking how a personal experience of discrimination can differ even if the situation and the personal background are practically the same: some people just do not recognize it as such. However, it took us by surprise that the feeling of discrimination was the highest in the most unexpected of places: in hospitals and at physical rehabilitation facilities. At the same time, we expected to find a much higher level of respondents who felt discrimination. Instead we have some 60 percent who answered affirmatively that they have not ever experienced discrimination. In fact, 63.3% percent of the respondents answered affirmatively that they have experienced discrimination at some point in their life.

Another important finding: the readiness to go to court with an individual discrimination case was significantly higher among those who felt that they had not been discriminated against. That says a lot.

What are you going to do with the findings of the survey? Will you present it to the general public through the media? Or do you submit the results directly to state institutions and bodies?

For this "survey" we will publish a brochure in which we present the results. We are also planning round tables across the country, gathering several municipalities together; putting the local NGO's together with representatives of local authorities.

What were the specific problems?

The length of the questionnaire is definitely something to seriously consider. Looking at it now I see that in some places we have repeated things or have asked the questions in such a way that the responses are unusable. This is where the role of an expert is crucial: they act as a guide, putting boundaries on the questionnaire. In addition, they can make sure that the questionnaire matches the general purpose you are trying to achieve with your research.

Yet, the more resounding problem is how to get a sample from a wider population. There is no database you can use, with names and contacts of people with disabilities of all ages and educational and geographic backgrounds. So, a wider sample was not really possible even though we tried our best to achieve it, even using the snowball method².

Not having a large source of data, we were forced to get our sample from the members of other organizations of people with disabilities that were willing to cooperate. Anyway, having mainly DPO members as the sample also produced biased results. Members of the disability movement are far more aware of human rights issues and discrimination than other people with disabilities and the results show that. For example, 26% of the respondents had higher education, whereas according to data shown in the Poverty Reduction Strategy Paper for Serbia (PRSP), only 7 percent of people with disabilities completed university - a striking discrepancy. The results of the "survey" also showed that in answering questions pertaining to household income, 42% of the respondents were below the official poverty line, whereas according to the PRSP, it is over 70%.

What would be your specific recommendations, by different stages in conducting a survey: the concept design, the implementation, results analysis, and the dissemination and use of the findings?

Only people with specific experience and training can administer surveys, there is no question about it. Also, in "surveys" like this, next time we will include the definition of the key concept; in this case, discrimination. If the participants had heard the definition of discrimination, their position might have been more clear and therefore of more use to us.

Also, the team of people administering the survey needs to be very well informed on the philosophy and the ideas behind disability issues. For example, they should be able to explain the social model, plainly and with ease. Also, whoever is planning to do a survey should definitely work with an expert to design the questionnaire. By expert, I mean psychologists and sociologists who have had experience carrying out this kind of research.

¹ The research conducted is more of a census of DPO members than a survey as the sample was not determined randomly.

² The snowball sampling method is a special non-probability method used when the desired sample characteristic is rare. It may be extremely difficult or cost prohibitive to locate respondents in these situations. Snowball sampling relies on referrals from initial subjects to generate additional subjects. While this technique can dramatically lower search costs, it comes at the expense of introducing bias because the technique itself reduces the likelihood that the sample will represent a good cross section from the population. More information available at: <http://www.statpac.com/surveys/sampling.htm>

This interview points to the need for experts in research to be involved in the data collection processes, particularly when developing survey questionnaires and analyzing the results. DPOs should look to universities and research institutes for expertise on these surveys to leverage their capacities in conducting quantitative research.

National authorities

In all three countries, ministries of social affairs are in charge of disability while ministries of education are responsible for disability and education issues. In all countries, it should be noted that disability is not a part of ministries of health even in terms of prevention or early detection strategies.

Disability policies that are developed based on statistical evidence as promoted by the OSCE is not widespread throughout the world and these three countries are not an exception. Most of actors interviewed from various line ministries presented the fragmentary information they had related to disability but did not express a need to develop further indicators. For instance, in terms of education of children with disabilities, in all three countries, the only indicator available is the number of children in special schools (a registry approach). This indicator is not very relevant for monitoring the promotion of inclusive education.

Similar observations can be made in terms of employment where the predominant indicator is a registry of the number of people working in sheltered employment or list of people registered with the national employment services. However, these indicators do not allow for the calculation of other indicators such as participation rates of people with disabilities in the mainstream labour force or the unemployment rate.

In terms indicators for social services, the situation is similar. The primary sources of information are registries of those who have access to social services or who are registered with centers for social work. Yet, no data on the most vulnerable part of the population with disabilities, those who are not registered or do not have access to services can be calculated. Classical indicators such as the coverage of social services cannot currently be calculated.

Policies oriented towards equalisation of opportunities and full participation of people with disabilities in cannot be monitored or evaluated with the existing tools. In all three countries these instruments for monitoring and evaluating policy implementation need to be developed and a strong investment in the development of indicators needs to become a priority for national and local authorities.

National Institutions

In Albania, BiH and Serbia, there are various national institutions that collect information on disability. They include the national disability pension fund, the national employment service and, in Albania, the National Health Institute. In all three countries, the national employment service incorporates a disability dimension in their database which means that information on disability can be disaggregated from their registries. Still this information is limited to only those who are registered within the national employment bureau.

The disability pension fund in Serbia is responsible for collecting statistical information on pension recipients. However, this data only delivers information on a sub-population of those who are receiving a disability allowance.

Centers for social work also have information on people with disabilities who have access to specialized services but they do not have information on those people with disabilities who do not have access to services.

It is clear that in the three countries, the information system on disability is based solely on administrative registries, a legacy of the former Socialist regimes. It was conceived for control purposes of financial flows such as disability pensions or allowance systems. It is also a by-product of the management of specialized institutions for people with disabilities including residential institutions, special schools and sheltered workshops.

International actors

There are several international agencies active in the region with a focus on developing statistical capacities. DFID and the World Bank are currently funding various surveys such as living standards measurement surveys (in Serbia), household budget surveys and labour force surveys (in BiH and Albania). These surveys present an excellent opportunity for gathering data on disability. With the inclusion of several questions on disability in each survey, significant information on the living conditions of people with disabilities can begin to be collected.

The development of disability statistics: Experience from Honduras with Thierry Gontier, disability statistics expert

Thierry Gontier, a statistician who worked in many countries on disability issues, spent many years in Honduras working in the field of disability. While in Honduras, Mr. Gontier was contracted to work with the national statistical institute (INE) to analyse the results of a large survey conducted with a disability module in 2001. In a discussion with Mr. Gontier about his experience, he explains how this project developed and what the significance of obtaining disability data was for Honduras.

Why did the government initiate the survey?

Importance of having disability data was identified by civil society in Honduras. When drafting the Poverty Reduction Strategy Paper in 2000, civil society pointed to the need for the creation of a national information system for persons with disabilities and to incorporate a module on disability within surveys produced by the National Statistical Institute on various aspects in order to identify among other things geographical location, socioeconomic and demographic characteristics of the population with disabilities.

In addition, there was a large consensus between the disability sector and the team in charge of the poverty reduction strategy as they both felt that collecting data in order to design appropriate programmes to fight discrimination made sense. Therefore, in 2001, the government did not have any objection to conducting a survey with a disability module.

How was the project carried out?

The first phase of the project was initiated by Handicap International in 2001 with UK Department for International Development (DFID). The first phase was the identification of the way to produce data on disability which included the design of a disability module with the participation of DPOs and relevant line ministries. Then, the survey itself had a sample of 13,000 households selected randomly and was carried out by INE within its regular budget.

By the time HI withdrew from Honduras at the end of 2001, the analysis of the results had not yet been completed. However, in 2002, Mr. Gontier was contracted by INE as a consultant to conduct the analysis of the survey results.

What are the main findings from the survey?

The answer to this question depends mainly on the end user of the information: for example, the Ministry of Health, it was enlightening for them to discover that 3 of 4 parents of a child with a congenital disability under 2 years of age have not yet detected the disability and cannot take appropriate measure when its time to reverse or limit the impairment. As a result of this finding, the development of an early detection program was a priority for the Ministry of Health.

For the Ministry of Education, they could not reach their international commitments of universal access to primary education without addressing the problem that the majority of children with disabilities were not completing primary school. In addition, the survey showed that the few children with disabilities enrolling in school having access to education do not have the specific attention they need and have lower rates of progression from their classmates without disabilities.

For the Ministry of Labour, the fact that the public sector was more discriminatory towards hiring people with disabilities than the private sector was important information. In addition, the high rates of employment of people with disabilities in the informal sector were also revealing for this ministry.

Probably the most significant results showed the link between poverty and disability in Honduras was strong. For example, the probability to become disabled is 3 times higher in poor household than in rich ones. The survey also showed the marginalization people with disabilities face through the lack of access to mainstream services such as education and health and the survey confirmed the limited coverage of specialised services.

By comparing the results of the survey with the public budget it was easy to demonstrate that the existing public policies and social expenses were not reducing the discrimination between people with disabilities and the rest of the population. In fact, the data showed that more public money is spent on non-disabled persons than on people with disabilities.

What did stakeholders do with the information once it was completed?

DPOs have seen that having official data that shows clear direct or indirect discrimination between people with and without disabilities was a powerful tool to defend their rights.

After having a presentation of the results of the survey, the Ministry of Education has begun to address the problem of access to education for children with disabilities. They have created a specific department to tackle the issue and have begun defining a policy. In the design of the policy, the ministry used detailed findings from the survey such as how household characteristics and demographics impact access to education. The survey also showed that attitudinal barriers in the family have a greater impact on access to education than the attitude of the teachers of physical accessibility of the premises. Finally, the data from the survey was also used to establish a baseline and provide an indicator for monitoring the policy.

In addition, international agencies such as UNDP and UNICEF made great use of this information in their reports in the design of their country programmes.

The development of these statistics is critical for guiding the development of disability policies and can serve as indicators for monitoring their implementation. However, it is vital that local DPOs are involved and aware of the development of such surveys so that they have a certain level of ownership on the data and are therefore, committed to using the results for lobbying.

THE IMPORTANCE OF DISABILITY STATISTICS FOR COMPREHENSIVE POLICY MAKING

Developing disability statistics that show the living conditions of people with disabilities including those who do not have access to the system is critical for the development of comprehensive disability policies aimed at equalisation of opportunities. Disability statistics must also make a comparison between disabled and non-disabled populations in order to show in-direct discrimination. This is extremely relevant in the region as countries begin to introduce anti-discrimination legislation.

To develop a set of statistical indicators in line with these new policies is also a clear challenge in the three countries. These indicators must be in line with the new social and human rights approach to disability. They cannot be limited to the existing information but should describe the living conditions of people with disabilities, the obstacles they are facing, measure the equalisation of opportunities and allow for the monitoring of their rights. In order to maximize this process, cooperation between statistical institutes, relevant line ministries and the DPOs must take place.

To calculate these new social policy indicators on disability, throughout the region, stakeholders will have to consider a different approach combining different ways of collecting information on disability. For example, in order to monitor the implementation of policies geared towards equalisation of opportunities in employment, there will have to be statistical indicators developed to measure access of people with disabilities to mainstream employment services as well as indicators on employment rates in the open labour market, retention rates at work and income levels.

Of course registers could still provide irreplaceable information on various aspects of disability services, but surveys are essential to get the general picture on the overall population. There is a strong momentum in the region for getting data on disability with the on-going surveys funded by the World Bank in all of the three countries. However, national authorities, central statistics offices and DPOs need to be involved in the process so that the information is relevant and useful to all stakeholders. The involvement of all actors will also be critical for instilling a sense of ownership within national actors so that they will analyze and use the data that is collected for policy-making, further research and lobbying.

Useful links:

UN Statistics Division Disability Webpage

<http://www.un.org/Depts/unsd/disability>

Washington Group

<http://unstats.un.org/unsd/methods/citygroup/washington.htm>

EUROSTAT

http://epp.eurostat.ec.europa.eu/portal/page?_pageid=1090,30070682,1090_33076576&_dad=portal&_schema=PORTAL

EUROSTAT (2001) Disability and Social participation in Europe

http://epp.eurostat.cec.eu.int/cache/ITY_OFFPUB/KS-AW-01-001/EN/KS-AW-01-001-EN.PDF



NEW! NEW! NEW! NEW! NEW! NEW! NEW! NEW!

Free Movement of People with Disabilities in South East Europe: An inaccessible right?

In the frame of the Disability Monitor Initiative, this report examines the prevailing policies and ensuing practices in South East Europe and how they impact the lives of people with disabilities given the obstacles they face in trying to participate in community life with the extensive barriers in the built environment. The report also looks at good practices happening in the field throughout the region. These initiatives are changing the environment in a positive way by removing barriers as well as by establishing individualised support services needed for greater independence. The report also looks at the capacity of these good practices to make more widespread change.

Editor's note

Within the Disability Monitor Initiative, Handicap International South East Europe created a regional journal to circulate current information on disability issues taking place in the western Balkans and to present the information to all disability stakeholders in an informative way. The journal will be printed quarterly and distributed in print and by email in Albanian, Macedonian, Serbian/Bosnian and English. The journal will also be available at: **www.disabilitymonitor-see.org**

For information or comments please contact us at: **editor@disabilitymonitor-see.org**

Tell us what you think about the Disability Monitor Initiative Journal.

Do you have something to add?

Do you find it useful?

Would you like to see something else?

We welcome your comments and feedback. Please send them to:

editor@disabilitymonitor-see.org