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“DISABILITY DATA IN THE CARIBBEAN”

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**HOW DISABILITY DATA ARE USED
AND
WHAT ANALYSES ARE NEEDED?
(A Non-Government Organization's Perspective)**

Ms. Beverly Beckles MOM., MRA

Chief Executive Officer

National Centre for Persons with Disabilities

Trinidad and Tobago

OVERVIEW

Within the Caribbean region, there has been a poor approach to the collection of disability data. This approach by key stakeholders in the field of disability, that is, Governments and Non-Governmental Organizations of and for persons with disabilities, has resulted in a marked deficiency in the availability of disability data. With the increase in the recognition of and willingness to improve the status of persons with disabilities in the Caribbean especially within the context of poverty eradication, the need for adequate, accurate, complete, reliable and timely information has become paramount.

Caribbean history will show that the work conducted in the field of disability has been mainly the responsibility of Non-Governmental Organizations (NGOs) of and for persons with disabilities and to a lesser extent that of the Governments of the region. Their roles in terms of advocacy, public awareness and service provision, research, policy formulation, development and implementation, program development and delivery are therefore pivotal to the development of persons with disabilities. In order to effectively carry out these roles these organizations need to have adequate, accurate, complete, reliable and timely information.

However, the emergence, purpose, structure of the NGOs and their inherent lack of financial and human resources have rendered most of them incapable of collecting, collating and analyzing disability data. This has contributed to the existing deficiency of relevant and reliable disability data which has hampered the effectiveness of these organizations over the years. They are therefore forced to plan policy and programme development, implementation, monitoring and evaluation of their operations without empirical data. The reality is that these organizations mainly depend on other agencies e.g. National Statistical Offices to provide relevant information.

While Governments have started to embark on action to address this problem, there is still room for NGOs by virtue of their role in the field to advocate for and participate in well-structured plans for addressing this problem.

The following presentation seeks to provide an NGO's perspective of the use of disability statistics in the Caribbean and the type of analyses which are to be made. It will therefore explore the following issues of: -

- ① **AVAILABILITY OF DATA**
- ① **ACCESS TO DISABILITY DATA**
- ① **HOW DISABILITY DATA ARE USED**
- ① **WHAT ANALYSES ARE NEEDED?**

AVAILABILITY OF DISABILITY DATA

Any discussions about the use of disability data in the Caribbean must start with an understanding of the availability of such data. The reality is that there is heavy reliability on data collection which is conducted at a national level. There has been and continues to be inadequacies in the type and quantity of statistical data whether through censuses, investigations or records from key institutions/agencies, which are utilized by persons with disabilities for example, education – special schools, health and social welfare facilities. Even organizations of and for persons with disabilities do not have structured systems or registries of members and clients. Of significance also is the lack of comparable data on a regional and international level as a consequence of the differences of definitions used, survey designs, methodology, and analyses.

Despite the inadequacy of disability data, the most common source of information available to NGOs is as follows: -

- **NATIONAL CENSUSES AND SURVEYS** - Of significance is the fact that it is only as recent as 2000 that most of the Caribbean countries have included specific questions on disability in their national censuses. This was as a result of a growing concern for the situation of persons with disabilities, which led to an agreement on

the part of several governments of the CARICOM region, non-government organizations as well as some international agencies. A major issue with this data in several countries is the fact that the baseline data on the disabled population has come under query. In Trinidad and Tobago for example, the 2000 Census has indicated that the disability population represented 4.1 percent of persons of all ages who were living in households or approximately one person in twenty-four. This figure is far below the World Health Organizations' estimate of 7 – 10 % of any population. There are some concerns about the reliability and hence the subsequent use of such data.

● **PUBLIC FACILITIES** - Health, social security, educational and other facilities which persons with disabilities utilize. In most cases, this information is not gathered with a specific purpose to facilitate research and dissemination of information to serve the users of this information. Therefore, the processes of compilation, collation and analysis are burdensome.

● **NGO's** - In most instances these organizations collect biographical data and create databases on their clients and members. Lack of knowledge and skills on the part of the organization affect their ability to provide the kinds of information which is necessary for their own survival. Apart from the use of national records, in order to get any real sense of the prevalence of disability there is the need to gather information from a variety of agencies, which work in the field of disability.

● **INDEPENDENT RESEARCHERS** - From time to time independent researchers conduct investigations on issues for which they have interest, either as students or scholars of the university or other institutions of learning, or for private purposes, in an effort to acquire funding from a particular agency.

ACCESS TO DISABILITY DATA

NGO's want and need easy access to disability statistics. However, a problem of access may occur for several reasons. NGO's by virtue of a lack of resources (financially) and a lack of capacity to undertake research must depend on other agencies to provide needed information. This however may not be available.

Additionally, in seeking information from individual agencies there may be hindrances when adhering to the policies which govern the dissemination of information of individual agencies. This factor may mainly be due to the issue of confidentiality.

Even in the cases where there is available data, the problem of access is evident firstly where there is difficulty of accessing the vast amount of existing data, held in the offices of National Statistical Offices, and secondly where there is a problem of interpretation and hence inefficient and ineffective use of the data.

Since NGOs do not have an influence on the research experts and the way most research is conducted they encounter problems with the data. The main areas of difficulty include the data collection process which sometimes does not reflect the full extent of disability, the level of processing, the research interests which basically dictate the analysis of the data and the form or format in which the available data is being presented. This factor can lead to conflict of views between NGOs and governmental agencies, especially if the analysis of data does not appear to be serving the needs of these organizations.

In most countries, the untimely nature associated with the release of social statistics especially, national statistics is common. Statistics are released long after the date of collection, making them outdated for some specific purposes. For the first time in the history of Trinidad and Tobago for example, the 2000 Population Census had provisions for collecting information on disability. However, the analysis of data became available to the public in 2005 and therefore this information will not give an accurate picture of the present situation, having had a four-year lapse. Delays in releasing census data mean

that many users of these statistics including NGOs must resort to the use of estimates. This action certainly affects effective planning and decision-making in these organizations.

Another problem of access includes the lack of computers and computer software and inadequate staffing skills of organizations especially in data analysis and the use of essential software packages. The Central Statistical Office in Trinidad and Tobago in keeping with the use of modern technology has posted the findings of the 2000 Housing and Population Census on its website. However, the capacity of individual users of this information will dictate their ability to make productive use of the information.

As stated earlier, independent researchers provide statistical data. However, not only is their work conducted for specific purposes and specific audiences, but there is the problem of knowing where to find or locate this information. The reality is that many of these works may never be made public or there may be a problem of access if the particular NGO does not fall within the specific audience base.

USE OF DISABILITY DATA

The use of disability data is integral to the work of NGOs. Though they have been relegated to the use of estimated figures there are several ways in which NGOs use the available data.

1. Fund raising is an important aspect of the work of NGOs since in many instances they are service providers and not for profit organizations. The history of the NGOs reflects that despite their contribution in the field, they are in many instances under-funded or not funded by the various Governments. In seeking funding, organizations must provide the statistical data, which highlights the extent of the problem or unmet needs being addressed as well as justify the need for the funding being requested from funding agencies.

2. NGOs depend on statistical data to enable strategic planning, formulation of organizational policies, development and implementation of projects and programmes to meet unmet needs, evaluation of their operations and justification of their existence. Further to this, available disability data are used for evaluating impact and sustainability of the work of these organizations.
3. The issue of advocacy is an important one for NGOs. These organization serve as the ‘guardians’ for persons with disabilities in the society. If they are to speak about integrating persons with disabilities within mainstream society and sustaining this inclusion then there must be proper identification of whom they are speaking about, what is to be done, and why. It is imperative therefore that relevant data is available and accessible for advocacy to be effective.
4. It is also necessary to be able to evaluate the social policies and programs formulated, developed and delivered by Government. It is not uncommon for differences in opinions to arise between policy makers and disability advocates about issues affecting persons with disabilities for example the number of person benefiting from any particular service provision of the state.
5. To be effective, NGOs need to monitor trends, which can affect the lives of their clients and members, trends not only in their country but regionally and internationally. This comparable data is often lacking in the Caribbean. Closely related to this issue is the non-existence of the documentation of best practices in the field where organizations can share experiences and expertise and lend support to the promotion of work, which is being undertaken.

WHAT ANALYSES ARE NEEDED?

There is an increasing demand for disability data. However, there has been a problem with a gap in the analyses which are needed by the users of the information and the available data. Any analyses of disability data must be disseminated in a timely fashion to serve the needs of the users. Additionally, consideration must be given to the complexity and multi-dimensional nature of disability; for example, different people experience disability differently as is the case of women and girls.

In the past, researchers have conducted research with little or no consultation with persons with disability. Consultation with NGOs is key to the identification of the type of analyses, which are needed since they are so intimately involved in the field of disability. In view of the dire need for the development, integration and inclusion of persons with disabilities in the wider society, critical analyses, which will provide relevant and reliable information to meet varied interest, must be made. Main analyses to be made include:

- The prevalence rates and causes of disability. Analysis should go beyond merely giving figures but being critical of all factors involved.
- The human rights issues of marginalization and exclusion. Analysis must look at inclusion based on equalization of opportunities in the areas of education, training, employment income distribution, social service provision, community, social, health and political issues just to name a few.
- The relationship between impairment and disability. There must be analysis of the level of functioning in the population with emphasis on the effects of the environment and the level of participation of persons with disabilities.
- There is still the need for a comprehensive exploration of the relationship between poverty and disability the Caribbean context.
- Comparisons of countries can never be underscored.

CONCLUSION

The importance of the collection, analysis and dissemination of disability data for the work of NGOs in the Caribbean cannot be discounted. The challenges, which these organizations face due to the lack of financial, and human resources to effectively undertake these activities, are common to all countries.

Most statistics users would like to see census data published and made available in a timely fashion. The establishment of national databases is essential to provide accurate information on people with disabilities and their situations, without which it is difficult to plan appropriate services and to monitor progress towards the achievement of full participation and equality.

Ultimately, efforts must be made by national governments to strengthen the capacities of the NGOs as well as to strengthen the capacities of those national statistical agencies on which they depend. These efforts will go a long way in ensuring that complete, relevant data is collected, processed, analyzed and disseminated to the key stakeholders in the field of disability.

References

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