Advocacy for Collecting Data on Disability in Population Census

Learning from India's Experience

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Supported by

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March 2014

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Chapter 1: Background

Lack of data on persons with disability is an issue of concern. Disability data has seldom been given due importance by governments, particularly in the developing/underdeveloped countries. Non-Governmental Organisations (NGOs) have largely focused on providing services and have not taken much interest on macro aspects such as the literacy rate, employment status and so on of people with disabilities. Moreover, there are many apprehensions regarding data on disability. Even the little data on disability that may be available is inaccurate due to many reasons such as a lack of awareness, the lack of standardised methodologies, a lack of knowledge of disability amongst the data collecting officers and so on. And therefore, as noted many times, data is just not collected regarding persons with disabilities. However, with the increased advocacy efforts of many Disabled People's Organisations (DPOs) to influence national policies and to monitor progress with respect to developmental goals for persons with disabilities, a definite need has emerged for authentic data on disability.

National Centre for Promotion of Employment for Disabled People (NCPEDP) is an advocacy organisation working towards promoting the rights of persons with disabilities in India. We have the experience of influencing two Population Censuses undertaken in 2001 and 2011 with respect to the inclusion of a question on disability. Our campaigns were not only aimed at including a disability question in the Census but also for creating awareness to ensure that people with disabilities get counted. The advocacy for Census 2001 witnessed, perhaps for the first time in the Indian disability history, a truly collective effort where disability organisations and networks from all over the country came together for an issue.

The advocacy campaign in New Delhi was carried out under the banner of the Disabled Rights Group (DRG). DRG is an informal cross disability advocacy network of organisations based in the National Capital Region which come together for common issues. The National Disability Network (NDN), which is a national network of NGOs/DPOs working in different States and Union Territories (UTs) of the country, was set up by NCPEDP in 1999. NDN Partners, apart from actively supporting the advocacy initiative at the centre, spearhead the movement in their respective States and UTs.

These campaigns have been a great learning experience for all who were involved. In this document we have narrated the advocacy experiences that we underwent while attempting to include disability in the Census.

1.1 The Purpose of this Document

- To understand the importance of data relating to persons with disabilities in Population Censuses.
- To share India's experience of the advocacy needed for getting the data of persons with disabilities included in the Population Censuses of 2001 and 2011.
- To analyse the experiences of including disability in Censuses in order to bring out the main learning regarding the advocacy strategies.

Chapter 2: Disability and Population Census

This Chapter discusses the importance of the Population Census in general and its importance for persons with disabilities in particular. The style adopted is in the form of answers to relevant questions.

2.1 What is a Population Census?

1) A Population Census is a count of the entire population of a country at a particular period of time, where data on each individual is collected. It is then analysed, published and disseminated.
2) Data is collected on factors such as age, race, sex, level of education, employment and income level, religion and language among others. The factors vary from country to country. Some countries have included disability as part of their Population Census.
3) The Census covers not only the settled population but also homeless persons and nomadic groups.
4) The biggest advantage of the Population Census is that it provides information regarding the characteristics of the population for the smallest administered areas of a country like the locality, block, village and town.
5) In most countries, the Census is conducted once every ten years.

2.2 How is data collected through the Population Census?

Different countries use different methods for collecting data (enumeration) about the population. These methods are listed below.[1]

1) Door to Door (face to face): In most countries, every household is contacted in person by a Census enumerator and enumerated.
2) Mailing: In a few circumstances, where an up-to-date and comprehensive address or population register exists or can be established, the enumeration process involves mailing out the Census forms and having the public mail back the completed forms.
3) Internet: Some countries use the Internet for people to engage in self-enumeration. However, it should be noted that this is

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[1] Page 55, sub section 14 - Plan of Enumeration, Principles and Recommendations for Population and Housing Censuses Revision 2, United Nations, New York, 2007

possible only if there is a high usage of information technology. Moreover, this method is always used simultaneously with more traditional ones to ensure that no one is left out.

2.3 What steps are involved in conducting a Population Census?

In general, the Census operations can be divided into six phases:

1) Preparatory work
2) Enumeration
3) Data processing
4) Building up of required databases and the dissemination of results
5) Evaluation of the results
6) Analysis of the results[2].

The preparatory stage is the most crucial from the advocacy point of view, as it involves budgeting, preparing the census calendar, preparing the questionnaire, conducting pilot census tests, planning for enumeration, publicity and communication, consultation with users, staff training and so on.

2.4 Who conducts the Population Census and who keeps the records?

In most countries there is a Census or statistical agency/bureau/commission, which is a national government body, in-charge of the Population Census. This agency is also in-charge of keeping the data and disseminating it.

2.5 If the information provided by individuals is shared and disseminated, how can it be confidential?

The information provided by individuals for the Population Census is collated and only the aggregate data is disseminated. For example, census data would give the total number of people educated/employed in a specific area or population and NOT information on what each individual has studied or what work she/he is engaged in.

Dissemination of data is strictly governed by laws and principles of that country regarding a Population Census. Sharing of individual information is prohibited as per the law in most countries.

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[2] Section 1.78, Page 28, Principles and Recommendations for Population and Housing Censuses Revision 2, United Nations, New York, 2007

2.6 How is the data from the Population Census used?

The Census information is used for planning, policy making and for administrative purposes. It is used by the Government (national and local), business, civil society, researchers and by those involved in providing facilities or services.

Census data helps the Government provide appropriate **services** like transport, healthcare, skill training and education facilities available to the public. For example, data on information about the mode of travel to work is used to improve public transport. The Census data can also help decide the number of schools that may be needed in a particular area. When a company/firm is considering new locations for setting up their offices, they look at the Census data to understand the availability of human resources, their skill levels and general information about a potential customer base.

The Census data also provides **insights into the inequalities** of the disadvantaged and vulnerable groups. For example, the status of women and the sex ratio; the status of elderly people and their living arrangements, their health status, their financial status and so on. The data also helps to see linkages between different characteristics of populations, as for example, the status of senior citizens with disabilities, the condition of women from marginalised castes/races, the health of children from a particular religion, and so on.

2.7 Why is it important for the disability sector to advocate for inclusion of disability in Population Census?

Getting included in the Population Census of the country is extremely crucial. Data is directly related to policymaking and resource allocation. Data is the first thing that policy makers at all levels look at. And it is the Population Census that helps us get a picture of the socio-economic status of persons with disabilities. Like mentioned before, the Population Census provides information about people in the smallest administrative block. Following are some of the benefits of having data on persons with disabilities.

1) To ensure **visibility**: Most people with disabilities in the developing world are confined to the four walls of their homes, due to lack of opportunities and accessibility. So people with disabilities are invisible. Hence, disability aspects do not figure in any development policies/programmes. When the official data reveals that there is a certain percentage, say x%, of people with disabilities, it immediately highlights the fact that there are a significant number of people whose needs have to be met.

2) To ensure **adequate resource allocation** (funds and human resources): Resource allocation is generally done on the basis of data. If the Government data reveals that x number in every 100 persons have a disability, then one can advocate for a proportional resource allocation.

3) To ensure **quantitative measurement** in order to evaluate the impact of programmes: Census data provides a basis to evaluate the impact of a particular initiative or programme over a period of time. For example, the Millennium Development Goals mention "education for all" by 2015. The Census data would reveal if the target is being achieved for persons with disabilities or not.
4) To help in advocating for **appropriate policies:** The disability activists often say, "We are the least educated or employed"; "We are the largest minority group" and so on. However, many times we do not have data to support our statements. If we are able to put a number to our statements and say, "only x% are educated" or "we are x% of the population", it makes a better impact in advocacy. Furthermore, the Population Census also allows for comparisons between the status of persons with disabilities in a country with non-disabled population. This helps to highlight the inequalities and the need to take adequate measures to bridge this gap.
5) To ensure **compliance with the CRPD**: For all the countries that have signed or ratified the CRPD, the lack of statistical data on disability would mean non-compliance with the CRPD. (Please see Box 1for the text of Article 31 of the CRPD, which is on 'Statistics and Data Collection').

2.8 What types of questions on disability are asked in the Census in different countries?

The questions on disability in Census are primarily of two types - (1) impairment based and (2) activity based. An impairment based Census question would ask people to identify themselves/family member(s) based on a list of impairment categories (for example, blindness, deafness, mental illness, autism and so on). An activity based Census question would have a list of major activities and people would be asked if they or their family member(s) have difficulty performing each of them (for example, climbing steps, self care, working at a job and so on).

Some countries have a generic Yes/No question in the beginning (before the question regarding the nature of impairment or difficulty in performing activities), asking if the person or the family member has a disability or a condition that prevents her/him from performing certain activities.

Some countries also have a third level of questioning related to the degree of impairment or difficulty in performing the activity (for example, people would need to identify from choices like mild/moderate/severe impairment or some difficulty/a lot of difficulty/cannot do the activity etc.).

Box 1

Convention on the Rights of Persons with Disabilities (CRPD)

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 in the collection and use 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 responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

2.9 What type of Question - impairment based or activity based - results in higher reporting of prevalence of disability?

Based on the experiences of different countries, the activity based question results in higher reporting of prevalence of disability than the impairment based question.

The possible reasons for getting a low percentage when asked the impairment based question, according to Daniel Mont[3] are:

1) First, the word “disability” has very negative connotations. People may feel stigmatised or shame if identified as being disabled.
2) Even if people do not feel stigma, the word “disability” often implies a very significant condition. Persons who can walk around their homes but are incapable of walking to the market may perceive their situation as not severe enough to be considered a disability.

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[3] Measuring Disability Prevalence – Daniel Mont, March 2007 (http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf)

3) Disability is interpreted relative to some unspoken cultural standard of what is considered normal functioning. This may vary across various cultures, age groups, or even income groups. For example, elderly people who have significant limitations may not identify themselves as having a disability because in their minds they can function about as well as they expect someone their age to function. However, at the same time, they may have significant difficulties performing basic activities.
4) The approach of asking about diagnosable conditions is also problematic. First of all, many people may not know their diagnosis, particularly when it comes to mental and psychosocial conditions. Knowledge about one's diagnosis is probably correlated with variables such as education, socio-economic status, and access to health services, thus introducing a potential bias in the collected data.
5) And finally, the functional effects of a particular condition can vary widely. For example, untreated diabetes can lead to profound functional limitations such as blindness or the loss of limbs. Diabetes that is properly managed can have a relatively minor impact on someone's life.

The possible reason for a higher percentage when one asks the activity based question is that a question such as 'Do you have difficulty walking?′ can pick up mobility limitations resulting not only from paralysis and amputation, but also serious heart problems or other medical conditions.

In the Zambian Census (1990) a simple "Do you have a disability?" type question yielded a disability prevalence rate of only about 1 percent. However, a functional based approach using the UN Washington Group Questions (described in the next question), yielded a disability prevalence rate of over 13 percent.

2.10 What is the Washington Group and what is the question that it has suggested?

The Washington Group (WG) on Disability Statistics was formed as a result of the United Nations International Seminar on Measurement of Disability that took place in New York in June 2001. WG was set up to:

- Foster international cooperation in the area of health and disability statistics.
- Develop disability measures suitable for censuses and surveys that will provide basic information on disability.
- Untangle the web of confusing and conflicting disability estimates.[4]

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[4] Development of an Internationally Comparable Disability Measure for Censuses; Washington Group on Disability Statistics (WG); 5th May 2008.

The WG membership agreed that a general prevalence rate that could be captured in a Census should address the "Equalization of Opportunities" purpose. The questions therefore focus on 4-6 basic/core activities designed to capture the great bulk of disabled adults. The recommended Census Question by WG is given in Box 2 below.

Box 2

The Census Question on Disability suggested by WG

The next questions ask about difficulties you may have doing certain activities because ofa HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?

Each question has four response categories:

1. No, no difficulty
2. Yes, some difficulty
3. Yes, a lot of difficulty
4. Cannot do it at all.

The severity scale is used in the response categories in order to capture the full spectrumof functioning from mild to severe.

2.11 How do we decide which question would be appropriate for our country?

The development of the most appropriate question is a continuous process and will vary from country to country and may even vary from Census to Census in the same country even though the WG question was designed to standardise the Census question across countries. The Indian disability sector did not choose the WG questions for the Census due to several reasons. (Please refer to Question 4.4 in Chapter 4.)

Some of the points that could be kept in mind while formulating the Census question are listed below:

1) How the Census data would be used?
2) What is the format of Census Questionnaire? It may have limitations related to the number of questions and the number of options/categories that can be included.
3) Who answers the Census questions i.e. whether each individual in a household reports for himself/herself or whether one person answers for the entire household?

Chapter 3: Advocacy for Census 2001 in India -The Confrontative Approach

We at NCPEDP successfully advocated for the inclusion of disability in the Census in 2001. We had to challenge the then Census Commission which had a view that it was impossible to include a disability question in the Census questionnaire. The story of the advocacy campaign has been given in this Chapter in an interview format in order to give a first-hand account of our experiences.

3.1 Was a question on disability included in Census of India before 2001?

Yes. Collecting data relating to disability dates back to the very inception of the Indian Population Census. The Questionnaire[5] of 1872 included questions not only on persons with physical disabilities but also those with intellectual disabilities and those affected by Leprosy. The practice was discontinued after the 1931 Census. No attempts were made to obtain such information in the Census of 1941 and the three decades that followed.

The comeback of a question on disability was in 1981 after a gap of nearly 50 years when the United Nations had declared the year as the International Year of the Disabled. The question in the Census of 1981 was whether people were any of the following: totally blind, totally crippled and/or totally dumb. The percentage of disabled persons that emerged at the national level was only 0.16%. The downside of this Census was that the doubts expressed about the reliability and accuracy of the data collected led to its discontinuation in 1991 i.e. no question on disability was asked in the 1991 Census.

3.2 You mentioned that the Census of 1991 did not include any question on disability. Was the Government planning to include it in the Census of 2001?

No. The Census Commission of India was not even considering the inclusion of disability as a category for data collection in the Census of 2001. We came to know that from the response to a letter we had written to the Census Commission.

3.3 What were your feelings when you read the letter of the Census Commission?

The letter from the Census Commission shocked us. It came as a setback to the optimism in the sector that had come with the

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[5] Historical Perspective, EQUITY, Volume 3, Issue 4, January 2001.

passage of The Disability Act, 1995 [The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act].

3.4 What did NCPEDP do?

We had only two options. The first was to accept their decision and sit quiet while the other was to challenge the decision of the Government. We spoke to a few leaders in the disability sector. They discouraged us saying that it was too late to bring about a change in the Census questionnaire (It was the month of December in the year 1999, about a year before the Census Enumeration was to be held, in early 2001). They said, "Even a comma cannot be changed in the Census questionnaire at this stage". We at NCPEDP were not convinced with their response. We decided to take it up with the Census Commission.

3.5 What steps did NCPEDP take to challenge the Government?

We realised that it is not going to be easy to challenge the Government. We needed facts to back our stand. A few like-minded organisations got together under the banner of DRG (Disabled Rights Group) and took the following actions:

1) **Educated ourselves**
   We got the past publications of the Population Census and National Sample Surveys. We also looked at The Disability Act, 1995 and the Ninth Five Year Plan[6]. We then prepared a note on Disability and Census. Around that time, by chance, we came to know about a workshop being held by the Ministry of Statistics & Programme Implementation (MSP&I), which is in charge of sample surveys, in association with the UN Statistical Institute of Asia and Pacific on Disability Statistics on 7th-11th February 2000 in New Delhi. It was a workshop on disability statistics and the disability sector was not even aware of it! One of the DRG members managed some passes using personal contacts. A few leaders from the disability sector attended this workshop, which was very informative. Our belief that disability should be included in the Census was strengthened.

2) **Communicated with the Census Commission**
   There was an exchange of letters with the Census Commission emphasising the importance of the issue. A meeting was also held between the Officers of the Census Commission and

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[6] Since Independence, the Indian economy has been premised on the concept of planning. This has been carried through the Five-Year Plans, developed, executed, and monitored by the Planning Commission. The period of the Ninth Five Year plan was from 1997 to 2002.

representatives of DRG on 18th February, 2000. It proved futile as the Census Commission refused to understand our views.

3) **Built a collective movement around the issue**
   We were clear that it would have to be a collective effort on the part of the disability sector. NCPEDP wrote to the National Disability Network (NDN) Partners asking them to immediately respond to the challenge.

   DRG members wrote to various disability NGOs and people with disabilities across the country sharing information, and asking them to also write to various Ministers and to the Census Commission. The response we received was overwhelming. Hundreds of letters and faxes from various organisations from all over the country poured into the Office of the Census Commission. It must be noted that the Core members of DRG met regularly in order to discuss every move and its strategic impact.

4) **Communicated with Ministries and Political Parties**
   Letters were written to the Honourable President, the Prime Minister, the Opposition Leader, the Home Minister (the Census Commission comes under the Ministry of Home Affairs in India), and other concerned Ministers expressing disappointment over the decision of the Census Commission and requesting the Government to reconsider the decision.

3.6 What were the arguments given by the Census Commission against inclusion of disability question in the Census and how was it countered?

The Census Commission was of the view that “It is difficult and impossible to collect data on disability through the Census”. Their arguments were the following:

1) The Census of disability was conducted in 1981 and was not successful. It did not give correct data of people with disabilities in our country. The Census Commission was made responsible for this failure and hence the practice was discontinued.
2) People with disabilities will hide their disability and their families will not be forthcoming with the information.
3) The disability question was not pre-tested. It was too late.
4) The enumerators were not technically qualified to diagnose the type of disability.
5) The Sample Survey was a better way to collect data on disability.

We countered the view, based on well-researched information, by pointing out that:

1) The questions in 1981 Census were inadequately framed and so the response was inadequate.
2) The job of the enumerator is not to probe but to faithfully record what the people have to say about their disability.

3) The Census does not happen in isolation. It should be backed by a major public awareness campaign by the Government.
4) The awareness level of people today is better than awareness levels twenty years ago.
5) The Population Census and Sample Survey are complementary to each other. There is no justification for an either/or approach. The broad data is obtained with the help of Census and then it is refined with the help of Sample Surveys.

Furthermore, we brought to their notice the Government's own Plan document (the Ninth Five Year Plan, 1997–2002), which had categorically stated that "To ensure planning for the welfare and development of the disabled more meaningfully, there is an impending need for the Office of the Registrar General and Census Commissioner, to revive their practice of 1981 Census to collect the data on the size of the population of persons with various types of disabilities and to make it available through the next Population Census of 2001 AD."

3.7 Based on the arguments put forth by the disability sector, did the Census Commission change its stand?

No. Almost a month went by after the meeting with the Census Commission in February 2000 and nothing positive materialised. There was no communication from the Government inspite of frequent follow-ups. It was clear that the Census Commission was stuck in its decision.

3.8 Was the strategy changed when the Government did not get convinced?

Yes. We decided to change our strategy - from the convincing/persuasive mode to a public demonstration mode. The reasons for changing the strategy were that:

1) Time was running out (There were only about 10 months left for the Census Enumeration to begin).
2) The Census officials continued to have a rigid mindset on the issue.
3) We were totally convinced that facilities, services and resources all depended on Census data.
4) We did not want to lose another ten years!

Hence, we decided to come out onto the streets to protest and make our campaign visible in order to garner public and political support.

3.9 How was the advocacy campaign intensified?

1) A huge Public Rally was organised in New Delhi on 7th March, 2000 to highlight the demand.
2) Media was mobilised in a major way. Both print and visual media gave very good coverage to the issue.
3) Political pressure was built by meeting with the then Leader of the Opposition Party, who gave immediate support to the issue

and wrote a letter to the then Home Minister on 31st March, 2000.

4) On 20th April 2000, to further intensify the pressure, a massive 'sit-in protest' was planned outside the Census Commissioner's Office.

3.10 What was the result of the campaign?

The campaign was successful. Two days before the scheduled 'sit-in protest', we received a call from the Home Ministry that a meeting had been scheduled under the Chairmanship of the Minister of Home Affairs. This was a major break-through. We decided to turn the 'sit-in protest' to 'solidarity sit-in', as it was difficult to call off the event at such a short notice. The opportunity was taken to brief the participants and the media about the developments.

3.11 What happened in the meeting with the Home Minister?

In the meeting with the Home Minister, the following key Ministers/officials were present i.e. the Statistics and Programme Implementation Minister, the Social Justice and Empowerment Minister and the Census Commissioner. From our side, select leaders from the disability sector representing different disabilities participated in the meeting. The meeting went on for about an hour. Various points were put forward and discussed. We had carried with us all the necessary documents to back our arguments. The Home Minister was convinced and assured the disability sector that the issue will be resolved very soon.

3.12 What did the disability sector do next?

Immediately after the meeting, an informal sub-committee was constituted on the spot, which met the next day in the Statistics and Programme Implementation Minister's Office. The Minister of Social Justice and Empowerment was also present apart from representatives from the disability sector. Together we drafted the disability question for the Census Questionnaire, which was then presented to the Home Ministry for a final approval.

3.13 When was the official announcement to include the disability question made?

About two months after the meeting with the Home Minister, on 10th June, 2000, the Government made the official announcement that a question on disability will be included in the Census of 2001.

3.14 What was the question asked vis-à-vis disability in the Census Questionnaire?

The Census Questionnaire included the following question on disability:

"If the person is physically or mentally disabled, give appropriate code number from the list below:

In seeing - 1
In speech - 2
In hearing - 3
In movement - 4
Mental – 5”

3.15 At what number was the disability question placed in the Census Questionnaire?

The question on disability was at the 15th position out of a total of 23 questions.[7]

3.16 So, did the work of NCPEDP on Census end at this stage?

Absolutely not! There was a greater task that lay ahead. We had less than six months to create awareness amongst people with disabilities and their families in a population of one billion to get themselves counted in Census 2001!

3.17 That seems to be a huge task! What was your strategy for awareness creation?

We immediately put together a plan to create awareness and also raised funds for the campaign. The steps we took were as follows:

1) **Regional Workshops** were organised in four regions of the Country - East, West, North and South. This was organised in collaboration with Ashoka Fellows[8] and NDN Partners. The partnership with Ashoka Fellows helped us to reach out to the larger civil society organisations and the NDN Partners ensured good participation of people from the disability sector. State level Census Officials also participated. At the workshop, State-wise groups were formed, which developed strategies for creating awareness on the issue in their States. Regional and local media were mobilised, which gave good coverage to the workshops.

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[7] Page 8, History of Census in India(http://censusindia.gov.in/Ad_Campaign/drop_in_articles/05-History_of_Census_in_India.pdf)

[8] Ashoka Fellows are leading social entrepreneurs who are recognised to have innovative solutions to social problems and the potential to change patterns across society. Ashoka Fellows work in over 70 countries around the globe in every area of human need. They work in areas of human rights, education, economic development, health, environment and so on.

2) **Awareness materials** were developed by NCPEDP and NDN Partners. These were also translated in local languages. These were:
   a. TV Spots: Three TV Spots were developed on the issue, which were aired in most of the national and regional channels during prime time. The channels aired them free of cost, as a public service.
   b. Several newspapers carried half and full page advertisements (designed by NCPEDP and NDN Partners), appealing to people with disabilities to get counted. The space was provided to us on a complementary basis (free of charge).
   c. Posters and pamphlets were designed and printed in large numbers. These were disseminated widely across various schools, colleges and other public places.

3) **The World Disability Day**, 3rd December 2000, was just two months before the census enumeration (February 2001) and it provided us an opportunity to use the occasion to create large-scale awareness on the issue. The common theme of Disability and Census was announced by us. NDN Partners in every State and Union Territory celebrated the day using the same theme. A huge event was organised in the heart of New Delhi, which saw participation of more than ten thousand people. A major mobilisation was carried out which ensured a very good participation in the event. Several schools, college students, youth, other groups and the general public attended the event.

4) We also wrote to **religious leaders** of all major religions to talk about the issue and appeal to people with disabilities to get themselves counted in the Census.

3.18 Was there any training and sensitisation of Census Enumerators?

Training of Enumerators was not done in a structured way. However, in some States where the State Census Commissioner was proactive and sensitive, our NDN Partners conducted training and sensitisation programmes for the Enumerators on the question on disability.

3.19 When did the Census Enumeration of 2001 take place?

The Census Enumeration took place from 9th to 28th February 2001.

3.20 What was the experience of persons with disabilities during the Enumeration?

Inspite of all the efforts, many persons with disabilities/their families from across India, shared that Enumerators did not ask the question on disability when she/he came to their homes. However, due to our awareness campaign, a few people made sure that Enumerators asked the question on disability. Some of us in the disability sector not only educated the Enumerators who came home but also made complaints to the local Census Office that Enumerators were skipping the question.

3.21 What disability figures emerged from the Population Census of 2001?

The Population Census 2001 data showed that[9]

1) Total population of India: 1,028,737,436 (1.03 billion)

   Males: 532,223,090 (51.7%)

   Females: 496,514,346 (48.3%)

2) Total population of persons with disability in India: 21,906,769 (21.9 million)

   Percentage of population with disability: 2.1%

   Males with disability: 12,605,635 (12.6 million or 57.5%)

   Females with disability: 9,301,134 (9.3 million or 42.5%)

Among the five types of impairment categories on which data was collected the following data emerged (number of people under each impairment category and the percentage with respect to total number of people with disabilities in the country):[10]

- Disability in Seeing: 10,634,881 (10.6 million or 48.5%)
- Disability in Hearing: 1,261,722 (1.26 million or 5.8%)
- Disability in Speech: 1,640,868 (1.6 million or 7.5%)
- Disability in Movement: 6,105,477 (6.1 million or 27.9%)
- Mental Disability: 2,263,821 (2.2 million or 10.3%)

3.22 Was the disability sector satisfied with the data of Census 2001?

The disability sector was not satisfied with the final figure (2.1% of the total population) as it was way below even the conservative estimate of 5%. However, if we compare it with the 1981 Census figure of 0.16%, it was a giant leap.

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[9] Office of the Registrar General and Census Commissioner, India, Census Population (http://www.censusindia.gov.in/Census_Data_2001/India_at_glance/popu1.aspx)

[10] Office of the Registrar General and Census Commissioner, India, Disabled Population (http://www.censusindia.gov.in/Census_And_You/disabled_population.aspx)

Chapter 4: Advocacy for Census 2011 in India - The Collaborative Approach

Unlike 2001, our advocacy approach in 2011 was collaborative, since the Census Commission was cooperative and open to discussions. This Chapter provides a brief look at our experiences of advocacy for improving the disability question and creating awareness in the Population Census of 2011.

4.1 When did NCPEDP contact the Census Commissioner for the 2011 Population Census?

NCPEDP contacted the Census Commissioner of India about a year before the Census of 2011, on 1st February, 2010.

4.2 Was the response from the Census Commissioner better than the last Census Commissioner?

Yes, the Census Commissioner was supportive. It turned out that the current Census Commissioner was earlier the State Census Commissioner of Tamil Nadu (a State in India), which was one of the few States which had done a lot of work in promoting the disability question in collaboration with our NDN Partner in 2001.

Sharing with us his concerns about Census 2011, he said that the result of the Pre Test of the disability question for Census 2011 was not satisfactory. He was open to inputs from the disability sector in order to ensure that the population with disability got accurately reflected in Census 2011.

4.3 What did NCPEDP do next?

We were happy that the Census Commissioner was supportive. However, the time was very short this time as well. We were asked to give suggestions for the disability question in about a month’s time. The following actions were immediately undertaken by NCPEDP:

1) **A Study on Disability Questions in Census**.[11] A Study was undertaken to understand the Disability Questions asked in the Census of a few other countries. Secondary data was compiled from the information available on the internet - websites of United Nations and some individual countries. The disability questions asked in the Census of about 11 countries (a mix of developed and developing countries) were compiled. In addition, the question recommended by the Washington Group was

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[11] Our Census, Our Future: Disability sector puts up a United Front, Disability News & Information Service, Volume 7 Issue 7 - April 01, 2010

studied. All these were tabulated for quick reference for further discussion. Then,

a. An objective-type Questionnaire, giving seven options [12] of disability question in Census was prepared.
b. The database of 100 disability leaders (covering different disability and regions) of India was compiled.
c. The Questionnaire was sent out to the leaders of the disability sector to select from the seven options the disability question that they thought was appropriate to use in Census 2011.
d. The data received was then compiled and analysed.

2) **A two-day Round Table Consultation**

A two-day Round Table Consultation was organised in collaboration with the Census Commission. About 100 delegates representing various disabilities from across various geographic regions of the country were present at the meet.

Consensus was reached on the following issues:

a. Unlike 2001, where mental retardation and mental illness were clubbed under one category, this time, in Census 2011, it was decided that there should be separate categories for mental retardation and mental illness (There were discussions about using a better term for mental retardation, like intellectual/cognitive impairment, but majority of the participants felt that people at the grassroots were more familiar with the term mental retardation or MR).
b. An option of multiple disabilities should be included.
c. There should also be the option of 'any other' (Many disability groups working in the area of Autism, Thalassemia, learning disabilities were keen that separate categories should be included to enumerate them. It was not possible to list all impairments, as there was a constraint regarding the number of options that could be included in the Census Questionnaire. It was then proposed that the option of 'Any Other' should be added.)

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[12] The following were the seven options:

Option 1. Disability Question asked in India Census 2001

Option 2. Disability Question asked in the Pre-Test Questionnaire of India Census 2011

Option 3. Disability Question based on the categories covered under the Indian disability laws

Option 4.Question suggested by Washington Group based on International Classification of Functioning, Disability and Health (ICF) (with certain modifications)

Option 5. Question used in UK Census 2001

Option 6. Question based on UNCRPD

Option 7. Question based on UNCRPD (with modification)

d. It was also proposed that the disability question should be higher in the sequence of questions (it was the 15th question in Census of 2001)

4.4 Was the Washington Group's (WG)[13]Question on Census considered? If yes, why was it not adopted?

Washington Group's Question on Census was discussed by the leaders with disability in India who attended the Round Table Conference. However, it was rejected due to the following reasons:

1) In the Census in India, the question on each member of the household is usually answered by the head of the family. So people felt that it would be culturally insensitive to ask questions about other members' ability to wash or dress their own self.
2) It was felt that many people living on higher floors of a building may say they have "lot of difficulty" climbing stairs. Similarly, the question on concentrating/remembering seemed vague. And, it was felt that the question on communication would not be understood by a lot of people. The questions were felt to be so general that the leaders with disability feared they might lose their purpose in the Indian context.
3) The concern of the leaders with disabilities was more on services for specific disability groups and therefore they wanted a question that would determine the number of disabled persons in different impairment groups which could then be used for advocating for more resource allocation and services.

4.5 What was the position of the disability question in the Census Questionnaire?

It was question number 9 in the Questionnaire of Census 2011 out of a total of 29 questions. In Census 2001 it was at number 15. The disability question was before the question on 'Mother Tongue'. This was seen as an improvement, as the probability of the question getting asked by the Enumerator would increase if it was one of the initial questions.

4.6 What was the Question on disability which got included in the Population Census Questionnaire of 2011?

The Question that was asked in Census 2011 on disability is given below.

"9(a) Is this person mentally/physically disabled?

Yes – 1
No – 2

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[13] Refer to Box 2 for details of the WG questionnaire.

(If the person has a disability, please put Code No. 1. If the person does not have a disability, put Code No. 2.)

9(b) If ‘YES’ in 9 (a), give code in the box against 9 (b) from the list below

In Seeing – 1

In Hearing – 2

In Speech – 3

In Movement – 4

Mental Retardation – 5

Mental Illness – 6

Any Other – 7

Multiple Disability – 8”

4.7 Was NCPEDP involved in the training of the Enumerators? How was it involved?

We were involved in the ‘Training the Trainers’ of Enumerators. The Census Commission's training followed a cascade (multi-stage) method. There were four levels in the cascade. The levels along with the number of people in each level are given below.

- National Trainers (NT) of whom there were 90.
- Master Trainer Facilitators (MTF) of whom there were 325.
- Master Trainers who numbered 54,000.
- Enumerators/Supervisors who numbered 2.7 million.

The NTs train the MTFs, who further train the MTs. MTs then train and handhold the Enumerators and Supervisors.

NCPEDP and NDN Partners were given a one-hour slot in the training programmes of the NTs, MTFs and some MTs. We developed a Training Module on the disability question. It was a 45-minute module. [14] We also organised a ‘Train the Trainers Programme’ for NDN State Partners and a few persons with disabilities, on the Module, who then delivered the training for the NT, MTFs and MTs. Some NDN Partners took the trainings up to district and village levels, based on their capacity and reach.

The training was also seen as an opportunity to create awareness about the issue. The training team comprised of 3 to 5 persons, representing different disabilities, who shared their experiences and barriers and how the Census could make a difference to them. The feedback that we received from the participants was overwhelming.

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[14] NCPEDP Training Module on Disability Question in Census 2011 (http://www.deoc.in/index.php/deoc-knowledge-services)

Not only did they understand the importance of the question and how it should be asked, but they also felt more informed about the issues and concerns of persons with disabilities.

4.8 What activities were undertaken for creating awareness among persons with disabilities?

The following were some of the activities undertaken by the disability sector for creating awareness among persons with disabilities and their families:

1) Two **Regional Workshops** (in Northern and Southern regions) and six **State level Consultations** were organised on 'Census and Disability' by NCPEDP in association with NDN Partners. In each of these workshops, about 100 persons with disabilities, representing different disability groups, participated to work out a strategy for spreading awareness about Census 2011 and the disability question. The banners carried a catchy slogan, "In Search of the Missing Millions".
2) A **Handbill** was prepared by a community based organisation which was translated in different languages.
3) **Rallies** were organised in some States by NDN Partners to create awareness.
4) **Television channels, radio stations** and **newspapers** were mobilised to talk about the disability question.
5) NGOs collaborated with **Self-help groups, women's groups, youth groups, village development committees**, etc.
6) NGO volunteers in some villages did **door to door campaigning.**
7) **Traditional media** like street plays were also used.
8) NGOs wrote to the **Governors** and **Chief Ministers** of the State for support in creating awareness.
9) A **video** on the issue was made by a federation of deaf groups in sign language and CDs were distributed. The video was uploaded on YouTube.
10) Some carried out **sms campaigns** and sent **postcards**.
11) Organisations providing services to people with specific impairments focused on creating **awareness among their beneficiaries and their families.**

4.9 Through this awareness campaign, were you able to take the message to every person with disability and their families in the country?

No. Though almost the entire disability sector came together, many areas still got left behind due to the limited reach of the NGOs. The coverage was not uniform. We depended on the Government to spread the awareness, particularly the Information and

Broadcasting Ministry, and wrote to them as well. However, the initiative from their side was minimal.

4.10 What were the experiences of persons with disabilities during Enumeration?

There were a few reports about Enumerators explaining the question and asking it. However, most people said that the Enumerator skipped the question on disability. Some people who were aware took the initiative to share the information with Enumerators who came to their house.

4.11 What would have been the possible reasons that the Enumerators did not ask the question, inspite of all the awareness that was created?

When we analysed the responses, the following possible reasons emerged.

1) When people with disabilities asked the Enumerator the reason for skipping the question on disability, some Enumerators said that this question was too sensitive or even offensive to be asked. It was clear that the training had not reached the Enumerators effectively. The direct reach of our trainings was only till the level of Master Trainer Facilitators and to an extent the Master Trainers. This meant that our trainings reached only the Trainers in the Training Cascade. At very few places did the training directly reach the Enumerators who would go from door to door collecting the actual Census data.

2) Many people reported that it was not just the question on disability but that many other questions were skipped. The Enumerators would ask only about 4-5 questions and fill the rest on their own making assumptions. For example, a lady working from home shared that her employment was not asked. It was assumed by the Enumerator that she was not working. Such assumptions would have been made for other questions as well.

4.12 What disability figures emerged from the Population Census of 2011?

The Population Census 2011 data shows that[15]

1) Total Population of India: 1,210,569,573 (1.21 billion)

   Number of Males: 623,121,843 (51.5%)

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[15] Census of India 2011, Primary Census Abstract, Figures at a glance, India (http://www.censusindia.gov.in/2011census/PCA/PCA_Highlights/pca_highlights_file/India/5Figures_at_glance.pdf)

Number of Females: 587,447,730 (48.5%)

2) Total Population of Persons with Disabilities: 26,810,557 (26.8million)

   Percentage of Population with Disability: 2.2%

   Number of Males with Disability: 14,986,202 (15 million or 56%)

   Number of Females with Disability: 11,824,355 (11.8million or 44%)

Among the seven types of impairment categories on which data was collected, the following data emerged (number of people under each impairment category and the percentage with respect to total number of people with disabilities in the country).[16]

- Disability in Seeing: 5,032,463 (5 million or 18.8%)
- Disability in Hearing: 5,071,007 (5 million or 18.9%)
- Disability in Speech: 1,998,535 (2 million or 7.4%)
- Disability in Movement: 5,436,604 (5 million or 20.3%)
- Mental Retardation: 1,505,624 (1.5 million or 5.6%)
- Mental Illness: 722,826 (7 hundred thousand or 2.7%)
- Any Other Disability: 4,927,011 (5 million or 18.4%)
- Multiple Disability: 2,116,487 (2.1 million or 7.9%)

4.13 Was the disability sector satisfied with the data of Census 2011?

No. We were not satisfied. We expected the percentage of population of persons with disabilities to be closer to the general estimate of 5%. The figure of 2.2% was a huge disappointment. We still have a long way to go to make the enumeration process more effective and improve awareness levels in society.

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[16] C-20 Disabled Population by type of Disability, Age and Sex (http://www.censusindia.gov.in/2011census/population_enumeration.aspx)

Chapter 5: Strategies for Effective Advocacy

Many DPOs are now engaging in policy advocacy across the world. We at NCPEDP have used advocacy as a strategy to get many policy changes, like access to voting, including disability in Census, etc. in India. This chapter documents the advocacy strategies derived from the campaigns of the Indian disability sector during Census 2001 and 2011. We have also included in this chapter some general points for carrying out various activities that need to be undertaken during an advocacy campaign (for example, writing a suitable letter, organising effective meetings and so on). These can at best be suggestions, as the situation in each country will be different. The various aspects of advocacy discussed in the chapter are:

5.1 Gathering Relevant Information
5.2 Engaging with the Larger Disability Sector
5.3 Engaging with the Key Policy Makers
5.4 Engaging with the Media
5.5 Raising Awareness

5.1 Gathering Relevant Information

For effective advocacy, gathering authentic information on the issue is very crucial. It helps not only in making an informed decision about an issue but also in putting forth the relevant points in a convincing manner to the policy makers. Some pointers for gathering authentic information are given below.

1) **Gathering information from the right source**.
    a. Identify the concerned Department in charge of the issue in your country.
    b. Get the correct names of the Head and other relevant official/s, their contact numbers, e-mail, fax number etc.

2) **Getting to know what is happening and when.**
    The timing of advocacy is crucial. In case of the Population Census, it would be the Calendar for the Population Census in your country. The right time would be at the Preparatory Stage, when the consultations are on for preparing the Census Questionnaire and before it's pre-test.

3) **Gathering up-to-date information about the issue.**
    In case of Population Census, one could write to the Census Office or use sources like the official website and any other authentic source. Written/printed information gathered from authentic sources is useful and considered more credible rather than hear-say. Those countries that have legislation on Right to Information (RTI) can use it to get authentic information.

4) **Ensuring systematic documentation.**

The documentation should be short and easy to understand so that it can be shared with DPOs, the media and so on and should be in a form where it can be referred to very easily in a conversation/dialogue.

A checklist of Questions for Census and Disability is given in Box 3.

Box 3

Checklist of Questions for Census and Disability

1) How does your country collect data on Population? Does it undertake a Population Census?
2) How often is a Population Census conducted? Which years? When is the next Census?
3) What questions are generally asked in the Census?
4) What are the laws/policies related to the Census?
5) Which Department/Ministry is in charge of the Census?
6) What is the name, address, phone, e-mail, fax of the concerned Minister, Census Commissioner/Office in charge of the Census?
7) What is the history of the disability question in the Census of your country?
8) What is the current official data regarding the population of persons with disabilities and their social and economic status?
9) What questions on disability are asked in other countries?
10) What are the international studies that have been undertaken regarding the disability question?
11) What options are available for the disability question in your country

(Some answers to the above questions which are global in nature are given in Chapter 2 'Disability and Population Census' of this document.)

5.2 Engaging with the Larger Disability Sector

It is generally seen that when a collective/network of organisations approach policy makers, it makes a better impact. It provides credibility to the campaign. To form such a collective it helps to reach out to different disability groups in different regions of the country. Further, in order to ensure that all organisations that are involved are on the same wavelength and to arrive at a consensus, a conscious effort needs to be made. Following are some pointers for effectively engaging with the larger disability sector:

1) **Developing a database** which is well represented, i.e., it includes:
   a. Persons with different disabilities, their parents and professionals (with the majority being persons with disabilities).
   b. Organisations of people with different disabilities.
   c. Persons with disabilities and organisations from neglected sectors like leprosy, deaf-blindness, psychosocial impairment, autism, etc.

   d. Representation from different Regions/States (Provinces) with both urban and rural representation.
   e. Representation of women with different disabilities and minority groups.

In addition, the database could have a list of other stakeholders like Government officials, people from the corporate sector, other civil society organisations, media etc.

2) **Ensuring effective information sharing and communication**
   a. Share all the information that you have gathered in a succinct manner with NGOs/DPOs.
   b. Share any thought/idea that you may have, and seek information/suggestions.
   c. Motivate people to respond and participate in the dialogue/discussions/campaigns.
   d. Acknowledge and respond to every mail/letter.
   e. Send out regular updates. Communication is the key for successful campaigns. So, you could make one person in-charge for communicating with NGOs/DPOs in the sector.
   f. Use e-mails/Social Network and other technology like Skype/video conferencing (if available) for communicating effectively with large numbers of people.
   g. Ensure accessibility of information and communication. For example, information can be made available in Braille/accessible soft copy, sign language interpreters can be employed in meetings, accessible websites can be designed, etc.

3) **Making joint decisions.** This ensures collective ownership of the issue at hand and provides one voice to the movement. It is important to include voices of people representing different disability groups. DPOs and NGOs are led by leaders who bring in diverse strengths, which contribute to the success of the campaign. A Core Group can be formed which meets regularly to take quick decisions.

4) **Getting more and more people involved.** This would not only help in building a robust disability movement, but also help in showcasing the group’s strength and solidarity in terms of numbers. It can contribute to turning a so called “non-issue” into an “important issue”.

5) **Budgeting sufficiently for information sharing**. It is important to budget sufficiently for photocopying, communication, translations, accessibility etc. Try not to cut costs at the expense of availability of information. You may send summaries but many times you may have to send all of the information when required. You may need to convert a hard copy policy document into accessible soft copy.

A collective movement for Census would help to take into account the concerns and needs of different disability groups and various socio-cultural aspects in framing the disability question, and also ensure that every individual with disability is counted during Census enumeration. Please refer to Box 4 below on some ways of engaging with the larger disability sector in a systematic manner.

Box 4

Some Ways to Engage with the Larger Disability Sector for Census Campaigns

1) To advocate for inclusion of disability in Census.
    a. Making joint representations to the concerned policy makers
    b. Undertaking joint campaigns
2) To discuss, debate and finalise the disability question in Census.
    a. Conducting Surveys
    b. Organising Roundtables and Meetings
    c. Constituting a Core Group to take joint decisions
3) To train Enumerators on disability and Census.
    a. Developing a Training Module
    b. Organising Training of Trainers
    c. Facilitating and conducting training programmes
    (Please refer to Box 7on Training of Enumerators)
4) To create awareness amongst Census Officials and the public regarding Disability Question in Census.(Please refer to Section 5.5 on 'Raising Awareness')

5.3 Engaging with Key Policy Makers

For making any policy change, DPOs have to engage with the policy makers. However, the approaches can be different depending on the situation. Some points for effectively engaging with the policy makers are given below.

1) **Having political knowledge helps in effective advocacy**. One should know which door to knock for which issue and the ways in which one can exert influence**.** This knowledge can be gained by reading newspapers regularly, interacting with the various officials/Ministers and understanding how various Government departments and systems work.

2) **Being alert in order to track/monitor developments**. Some Governments may not be communicative or even transparent. Hence, DPOs would have to be proactive to get the required information in formal and informal ways. Following the media closely also helps in keeping abreast with developments.

3) **Ensuring effective communication** for engaging with the Government. Some methods of doing so are given below.

   a. Letters: It generally starts with a letter, asking for information or stating our requests. (Please refer to Annexure 1 on tips for effective letter writing to the Government).
   b. Memorandums/ Demands: A crisp document listing the demands very clearly.
   c. Meetings: Formal and informal meetings with the Ministers/Officials (Please refer to Annexure 2on tips for organising an effective formal meeting with policy makers)

4) **Making right political connections**. Prior political connections are not a must for advocacy but could be useful if used in an effective way. These could also be cultivated over time. There may be political leaders who are 'friends of the disability sector' because of the sensitivity and support that they may have given in the past to the movement or because they or their family member may have a disability and so are sympathetic. People in the movement may have contacts with different policy makers (at the national/ state / local levels). They could be mobilised to influence the decision maker/s.

5) **Strategizing your campaign**[17]. If the Government and you are on the same side, then cooperative and collaborative strategies help in meeting the end more effectively. When the strategies of dialogue and persuasion fail, the disability sector could change its strategy and make it confrontative. Different countries will have different ways of expressing this difference. One of the ways of expressing difference and creating visibility to the issue could be public protesting (peaceful/non-violent). Decisions to organise protest rallies/sit-ins/hunger strikes have to be planned after much thought. Annexure 3 gives pointers on how to organise a Protest Rally. Litigation is also a tool that can be used to fight for rights/justice.

For inclusion of disability in National Population Census, one would have to engage with the Department/Ministry which is in-charge of Population Census. One may also need to engage with legislators in case of any advocacy that may be required for policy decisions related to disability and Census. It is also useful to engage with policy makers from various other relevant Ministries, like

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[17] Najam has examined in his paper the interactions of the Third sector with the government. His paper has proposed a 4C framework based on institutional interests and preferences for policy 'ends' and 'means' i.e. cooperation in the case of similar ends and similar means; confrontation in the case of dissimilar ends and dissimilar means; complementarity in the case of similar ends but dissimilar means; and co-optation in the case of dissimilar ends but similar means.
Adil Najam, 2000, The four C's of Government - Third Sector Relations: Cooperation, Confrontation, Complementarily, Co-optation (http://www.sdpi.org/publications/files/R25-The%20Four%20Cs%20of%20Government-Third.pdf)

Information, Rural Development, Social Justice and local administration for spreading the message.

Box 5

Some ways of Engaging with Policy Makers for Census Campaign

1) Proactively reaching out to the Census Office to gather information and discuss the issue of disability and Census.
2) Being a part of the Committees/Consultation incase the Census Office has formal ways to engage with stakeholders.
3) Inviting Census officials to conferences/workshops/meetings to share and exchange information.
4) Working together for framing the Disability Question.
5) Partnering in training Enumerators and Census Officials on Disability Question (Please see Box 6 for pointers related to training enumerators.)
6) Planning Awareness campaigns for Census

Box 6

Training of Enumerators

1) Training of Enumerators is critical to ensure that the Enumerators do not skip the question on disability. Many Enumerators have apprehensions about asking this question because of the stigma attached to disability. And, the training helps to tackle these apprehensions.
2) The Census-in-charge in your country can help you to plan and prepare the kind of Training Module which would be most effective. The content, delivery methodology and duration would depend on the arrangements that are available for training. For example, one can have face to face training or online training. One can make use ofa projector, board and chalk, computer, email etc. It would be best that disability training is part and parcel of the general training programme for the Enumerators. As there are several questions in the Census, the training time available for disability would be short. Hence, the Training Module on disability should be short and crisp.
3) Include persons with disabilities as trainers as it leaves a lasting impact. Allocate time for people to ask questions.
4) It is important to translate the training material in local languages and conduct the training in an easy to understand language. Some areas may not have the equipment for an audio-visual presentation, so prepare a module that could also be delivered without any technology.
5) Ensure that the training module is made available in accessible formats as there would be people with disabilities (officials and Enumerators) amongst the trainees.

5.4 Media for advocacy in Census

Media is a powerful tool for advocacy and awareness. It can be used effectively for Census campaigns. The media helps

1) To create **pressure** on policy makers.
2) To **share information** regarding the issue and the developments. Media can be involved at every step of the Campaign. Information regarding the first meeting with the Census officials; findings of any study on Census; information about conferences, can all be shared with the media. This can be done through press conferences, press releases and interactions with media persons. Well-researched information helps to bring out very compelling editorials and full page features on the issue.
3) To **motivate people** to participate in the Census. Media is also a very powerful medium to send out messages to all corners of the country. Awareness can be raised through various means like reports, print advertisements, television and radio spots, social media and so on.

Some pointers for engaging with the Media are given below.

a. **Making 'friends' with media**. Continuously engage with the media, keep them informed and educated. Over time, some media persons become advocates for disability issues.
b. Preparing and maintaining a **database of media persons** involved in print, audio and visual media.
c. Organising **Press Meets** at central locations, like the press club etc., where it is easy for the media persons to reach.
d. Ensuring a comprehensive **information package** to journalists, including press releases (which are official statements issued to media giving information on the particular matter) and other relevant documents organised in a systematic manner to ensure that journalists have all the information handy to write their reports. Give your name and contact details (including mobile numbers) in press releases for any further information/queries/ interviews. You could add a note pad and pen for the convenience of the journalists. Always prepare extra information packages which can be distributed later. Send press releases to those publications which did not come to the press meet.
e. Taking all the **relevant information** with you during an interview/debate. This adds credibility to the information that you share.
f. Reaching the **regional and local media** through partners.
g. Scanning (search) all the papers, publications and websites and **collating press reports** to not just document but to analyse the coverage in order to further strategise.
h. **Developing a website** to keep people informed and to have all relevant information at one place.

5.5 Raising Awareness

Creating awareness is an integral part of any work that one does in the disability sector, as lack of information and negative attitude are major barriers for people with disabilities. The aim of awareness campaigns for Census could be two-fold, that is,

- To integrate disability aspects in the general awareness campaign in Census.
- To have specific campaigns for creating awareness on the disability question in Census.

The following questions may help in building your awareness campaign for the Census:

1) **What is the information that you want to give out?** The content of the awareness campaigns would include general information about Census and specific information about the question on disability. It could cover the importance of the Census, the period of enumeration, the confidentiality of the collected data, what to expect when an Enumerator comes to your house, what is the question on disability, the importance of answering all the questions, and so on.

2) **Who your target group is?** The target groups for raising awareness would include:
    a. Disability organisations (NGOs/DPOs/ Self-help groups)
    b. Persons with disabilities and their families
    c. Government officials
    d. Other Civil Society organisations/groups
    e. General Public

    Special attention should be paid to reach out to those specific communities/groups who may get left out, like, elderly people, women, those with invisible disabilities, homeless people and so on. The method for raising awareness may vary for each target group.

3) **How to maximise your reach?** Strategic collaboration would be the key to maximise the effort. The endeavour should be to send out a common message using the various mediums. One can form partnerships for creating awareness. One could collaborate with the following institutions.
    a. **Government:** It is not just the Social Justice or the Ministry that is responsible for disability, but also other Ministries like Information and Broadcasting, Rural Development, etc., which can play a major role. The Census Commission itself would have a budget for creating awareness and they could organise a focussed campaign on the disability question.

    b. **DPOs and NGOs:** Local organisations help in reaching out to different disability groups and different regions in the country. While each organisation might have a limited reach, collectively they can reach a large number of people. Moreover, the knowledge that these organisations have of the local language and specific socio-cultural dynamics help to take the message to every individual in the communities where they are based. These organisations can also connect with the local leaders, teachers, and other stakeholders for spreading the message. They can educate the Enumerators and help them in collecting the data.

c. **Civil Society Organisations**: Organisations working on the Census with respect to gender, elderly people and other minorities can be encouraged to include disability as part of their campaigns.

d. **Media Houses**: The media can play a very crucial role in creating awareness on Census.

4) **What are the means of creating awareness?**
   a. **Print, audio** and **visual media:** Radio, Television, Newspapers, Magazines etc.
   b. **Internet** and **Social media:** Website, YouTube, Facebook, Twitter etc.

   c. **Local mediums**: Street plays, puppet shows, dance-drama, local festivals, handbills, posters, announcements in local language, etc.

   Ensure that you use accessible formats while developing awareness materials that is, ensure information is present in sign language and in Braille, put captions in television spots, develop easy to understand messages and pictorial information, develop an accessible website, etc.

5) **When should one focus on awareness raising?**
   Though information sharing is a continuous process, a focussed campaign can start two to three months before the actual enumeration and should continue till the last date of enumeration. Plan and strategise the awareness campaign at least one year in advance in order to raise a budget, develop materials and to make strategic partners.

Annexure 1

Pointers for Writing an Effective Letter

1) **Content of the letter**
    a. The purpose of the letter should be stated clearly in the beginning of the letter. An effective subject line is useful to set the context.
    b. Use the appropriate title of the person to whom the letter is addressed, for example, Mr./Ms./Honourable, etc.
    c. Give a brief introduction about yourself and your organisation or network or group in the letter.
    d. State your request in a clear and succinct manner.
    e. In case you want to give details, these can be attached as annexures, in which the important points can be highlighted.
    f. Ensure that the letter has your correct contact address, phone number, e-mail ID so that the person can respond to your letter.

2) **Delivery of the letter**
    a. You can mark 'Urgent' or 'of High Importance' to increase the probability of the letter being given due attention by those who receive it.
    b. Ensure that the letter reaches the concerned person (deliver by hand/fax/e-mail). Receipts/delivery slips of courier/post/fax are useful to keep in the record. Copies of the letters sent/received should be saved properly for easy reference.
    c. Follow up by calling the concerned office to ensure the receipt of the letter.

3) **Reminder letters**
    a. In case of non-response within a certain period of time, it is useful to send a reminder in the form of a letter/e-mail. You could even attach a copy of the previous letter for easy reference.

Annexure 2

Pointers for Having an Effective Formal Meeting with Policy Makers

1) Take an appointment for the Meeting.
2) Form a delegation that is well represented. The constitution of the delegation would depend on the context at hand. If the demands require focussed discussion then ideally only a few members should be present. If it is a national level policy demand, members from different regions would add value. For issues that affect all people with disabilities, a cross disability delegation would be more appropriate.
3) All the delegates should have a brief discussion amongst themselves before the meeting to decide how the meeting should proceed. Decide who will do the opening; how much the time each delegate can take to share her/his views; how to stay on the topic and so on.
4) Take all necessary permissions required in your country. For example, in India, one would need passes for each delegate, an escort and an interpreter to meet officials/politicians; permissions for special parking, cameras, mobile phones, etc.
5) How and when to involve the Media should be decided by the delegation. That is, one can decide whether they will be part of the delegation or whether there can be a media brief/press release after the meeting.

Annexure 3

Some Pointers for Organising Protests

1) The purpose of the public protest needs to be clear and well thought out (the demands being made as well as the authority against whom the protest is being done).
2) The form of protest should be thought out. There could be many ways of protesting, that is, through a rally, a candle light vigil, courting arrest or some other innovative and non-violent method, that can be adopted to attract the attention of the policy makers, media and the public at large.
3) Mobilising a large number of people for the public protest is important to bring visibility and credibility to the issue.
4) The decision to organise a protest and the reasons behind it needs to be communicated to the policy makers and the media.
5) Permissions may be required from various authorities.
6) Sharing of relevant information helps to not only gain the support and participation of larger public but also adds to the credibility of the movement. The information could include purpose of the rally, chronology of what has happened so far and the demands.
7) Logistics have to be carefully planned and organised for street protests (i.e. mobilisation, the venue, permissions, media, emergency preparedness, microphones, photographers, slogans, pamphlets, press kits, banners/placards/ flags, tea/snacks, etc.). These would vary based on the nature of protest.
8) Since protests are organised in public areas (roads/streets), logistics may not be always under the control of the organisers. People who join the protest should be aware of possible problems that they could encounter – from standing for long hours, no chair, no accessible public toilets to police using force to disperse, etc. Organisers should share what to expect and the do’s and don’ts with the participants. At the same time, the organisers should do their best to mitigate any problems that they anticipate. There should be a few leaders who should be in charge and they should be very alert. They should be in constant dialogue with the police and others and should communicate what’s happening with the participants. The organisers should make every attempt to ensure the protest is very peaceful. The purpose is to attract attention and not to harm anybody.

Some useful Links and Resources on Disability Statistics and Census

International Resources

1) Principles and Recommendations for Population and Housing Censuses, Revision 2, Department of Economic and Social Affairs, Statistics Division, United Nations, 2007 (http://unstats.un.org/unsd/demographic/sources/census/docs/P&R_%20Rev2.pdf)

   The United Nations recommends that all countries or areas of the world produce detailed population and housing statistics for small area domains at least once in the period 2005-2014, around the year 2010. For most nations that means conducting a traditional census. This document focuses on the traditional census while also describing other approaches for generating reliable statistics on population and housing. Pages 212 to 219 in this document talks about Disability Characteristics.

2) Convention on the Rights of Persons with Disabilities. Article 31 is on Statistics and Data Collection (http://www.un.org/disabilities/default.asp?id=291)

3) United Nations Enable Website

   (https://www.un.org/disabilities/default.asp?navid=13&pid=1515)

   The section 'Disability and Statistics' provides many useful resources and links.

4) Training Manual on Disability Statistics, United Nations, WHO and ESCAP, 2009 (http://unstats.un.org/unsd/censuskb20/Attachments/2008ESCAP_TrainManDisabty-GUID7c07895389164cdab0b0b7609136f117.pdf)

   This Training Manual provides an overview of the International Classification of Functioning, Disability and Health (ICF) framework for disability measurement as well as implementation guidelines on disability data collection, dissemination and analysis.

5) Washington Group on Disability Statistics (http://unstats.un.org/unsd/methods/citygroup/washington.htm)

   The main objective of the WG 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. The aim is to provide basic necessary information on disability which is comparable throughout the world. For the primary purpose of informing policy on equalization of opportunities, the WG has developed, tested internationally, and adopted a short set of disability measures suitable for use in censuses, sample-based national surveys, or other statistical formats.

6) Documents of Washington Group on Disability Statistics (http://www.cdc.gov/nchs/washington_group/wg_documents.htm)

Documents of the Washington Group on the topic of Disability Statistics such as, the WG Purpose Paper, The Matrix, Understanding and interpreting Disability, Monitoring the UN Convention, Recommendation for 2010 Round of Census, Short Set of Questions and Extended Question Set on Functioning etc., are available at the above link.

India Resources

1) Website of Office of the Registrar General and Census Commissioner, India, Ministry of Home Affairs, Government of India. (http://censusindia.gov.in/)

In the section "Archive", there is data on Census 2001 (Census data online). Census 2011 data, including the presentation on "Data on Disability"(December, 2013) is available on the Home Page.

2) History of Census in India (http://censusindia.gov.in/Ad_Campaign/drop_in_articles/05-History_of_Census_in_India.pdf)

3) "Census includes category 'disability' for first time!" and "Fight to stand up and be counted". (http://ncpedp.org/policy/pol-break03_old.htm)

These articles briefly describe the advocacy campaign of NCPEDP to include Disability Question in Census of 2001.

4) "Our Census, Our Future: Disability sector puts up a United Front", Disability News & Information Service, Volume 7 Issue 7 - April 01, 2010(http://www.dnis.org/features.php?issue_id=7&volume_id=7&features_id=173)

At the end of the Feature Article, NCPEDP's Research Study on the Disability Question on Census 2011 is available.

5) NCPEDP's Guidebook for Training of Enumerators on Disability and Census (http://www.deoc.in/index.php/deoc-knowledge-services)