

WRONG QUESTIONS, WRONG ANSWERS
THE STATISTICAL BARRIER TO ACCESSIBILITY

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SUMMARY

It is now widely estimated that approximately 10% of the world's population are people with disabilities (over 650 million people). It is also recognised that approximately 80% of people with disabilities live in developing countries.

This is fine as an attention grabbing statistic but it doesn't tell us very much about what is happening in individual regions or countries of the world, nor does it give policy makers a clear basis for action or prioritisation.

The difficulty is that the attention which is paid to the needs of people with disabilities by governments varies greatly around the world. In some countries or areas, disability issues are given a high and sustained political focus which is backed up by improvements in accessibility to transport systems as well as in many other areas such as education, health care and employment. In others, there is scant attention paid to disability as either a social or economic priority.

There are many reasons for this wide variation but one fundamental factor is the widely different base on which the statistics on the numbers of people with disabilities are gathered in different countries. Estimates of the prevalence of disability range from 20 per cent of the population in Australia to just 1 per cent in Kenya. Intellectually and intuitively we all know that this cannot be right.

We also know that for politicians faced with acute economic pressure, the lower the number, the lower the level of interest and commitment to address need. It can be noted that there is a strong correlation between the recognised numbers of people with disabilities and the legislation put in place to address access and other issues.

The reason for the discrepancies is in large part the nature of the questions that are asked to determine whether an individual has a disability and how that disability impacts on his/her life chances.

This paper explores the discrepancies that exist and the impact they have on both the political and practical focus that is given to accessibility issues in transport as in other sectors. The paper also suggests changes that could be made to enable

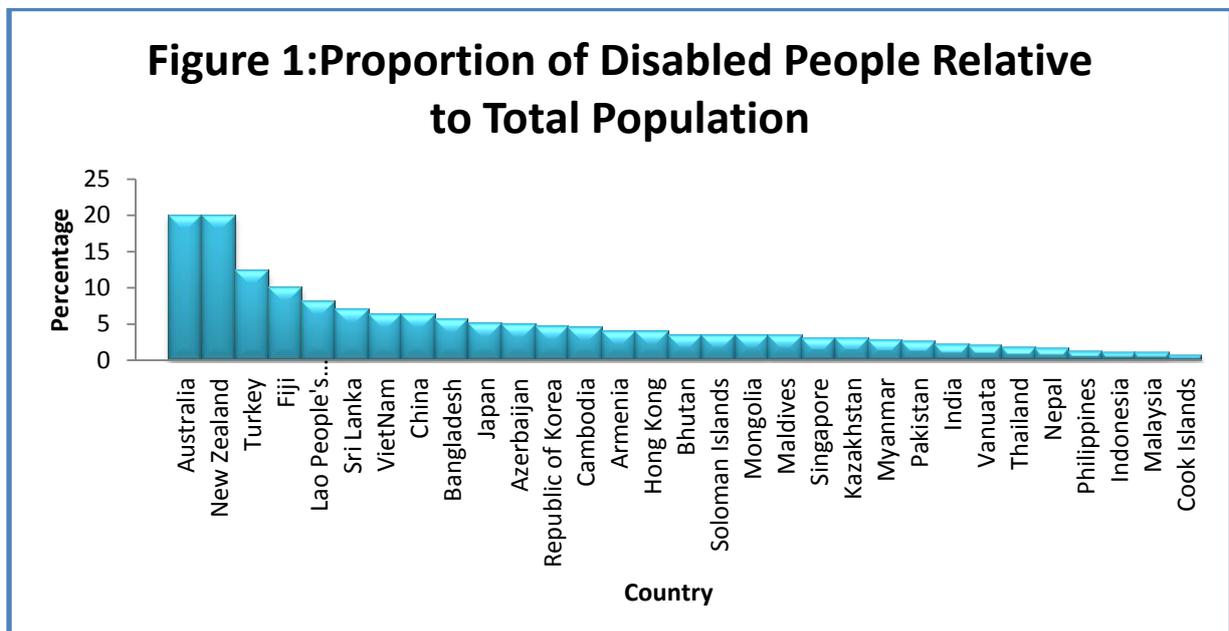
practitioners and politicians to have a clearer and more accurate understanding of the scope and nature of disability as a sound basis for action.

ASKING THE WRONG QUESTIONS

The Convention on the Rights of Persons with Disability (CRPD) emphasises the continued need for reliable and comparable data on people with disabilities (Article 31). This article requires that governments collect appropriate statistics to facilitate the monitoring of the CRPD and that they develop and implement national policies and programmes promoting the rights of persons with disabilities.

A study for the World Bank [Mont, D 2007, “Measuring Disability Prevalence”] drew attention to the wide variations across the world in the way that statistics on disability are gathered. These range from medical/condition based categorisations through to functional and “activity limitation” based questions. The result of these different approaches is a significant difference in the level of disability recorded. As noted above, estimates range from 20 per cent of the population in Australia to less than 1 per cent in Kenya. Between these two extremes are many other examples which look to anyone with experience in this field to be wholly counter intuitive.

Figure 1 below illustrates the enormously wide variation in the countries of Asia and the Pacific



Source: UNESCAP, 2010

The difference that can be made by changing the nature of the questions asked is illustrated in Brazil. At first the National Census asked about a specific set of medical conditions. This was later changed to ask about functional difficulty in carrying out various activities. The second approach led to an increase in the estimate of the

prevalence of disability from 0.9 per cent to 14.5 per cent. This has had a profound effect on Government policies.

Worldwide these discrepancies have a major impact on the level of political interest that is given to the subject of disability. In the field of transport and mobility they also have a major impact on understanding at practical and technical levels of the barriers that need to be removed to enable disabled people to live independently.

The difficulties created by the lack of consistency in data collection are highlighted in a United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) report [UN ESCAP, "Disability at a Glance 2010: A Profile of 36 Countries and Areas in Asia and the Pacific"]. The report notes that "*definitions of disability, methods and institutional capacity regarding data collection vary considerably. Consequently the comparability of the data across the region is called into question.*"

The Report goes on to assert that, in spite of these shortcomings, such data can still reveal valuable information at a regional level. It does, however, call on Governments, researchers, organisations of people with disabilities and other stakeholders to take further action to "*enhance their data collection efforts and create an inclusive, barrier free and rights based society.*"

The UN General Assembly has also reiterated the urgent need to include disability in the international development agenda, and has identified the strengthening of the collection and compilation of national data on the situation of people with disabilities as a means to achieve this goal.

The UN notes that disability continues to remain largely invisible in most mainstream development processes. They stress that better information on the situation of people with disabilities is urgently needed to prevent the perpetuation of barriers to participation and inclusion, and to help towards the overall objective of equalisation of opportunities.

It is clear, however, that this is not a new issue. As long ago as 1981 the UN published Guidelines on this topic [UN, 2001, "Guidelines and Principles for the Development of Disability Statistics"]. At that time it was noted that "*Over the past several decades, national efforts to collect disability statistics have increased significantly. However, this increase is due mainly to the inclusion in the census of a question or questions on disability. Some countries have included a special module on disability in an ongoing survey, usually a health survey. Only a few countries have undertaken a special disability survey. National registers of persons with disabilities are rare, and another problem is the lack of international standards to guide the production and compilation of statistics in the field of disability. As a result, the quality, completeness and detail of existing statistical information are usually inadequate for national policy and programme needs.*"

In the years since that guidance was published, there is certainly evidence of data on disability being gathered more routinely in more places, but the fundamental problem of the questions that are asked and the impact that the resulting data has on policy and practice remain.

The UN Convention is clear that disability results from an interaction between a non-inclusive society and individuals. Indeed this is the basis of the long established social model. But until we start to measure the extent to which non-inclusive societies – in all their forms – are impeding the daily living of people with disabilities we will not have a clear basis on which to establish priorities for action.

It has been argued that dividing the population into disabled and non-disabled people, although useful for many purposes can also be problematic and can contribute to a focus on negative differences in abilities. However, if we focus the statistical analysis on activity limitation it takes on a much broader perspective and one that enables us to focus on where and how changes need to be made to remove the barriers that have created that limitation.

As a 2005 report [Eide, Arne and Loeb, Mitch, 2005 “Data and statistics on disability in developing countries” Disability Knowledge and Research Programme] comments *“Comparative statistics is particularly powerful as a tool for lobbying, sensitising and influencing decision makers as well as the population in general”*.

The Washington Group 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. An outcome of that meeting was the recognition that statistical and methodological work was needed at an international level in order to facilitate the comparison of data on disability cross-nationally.

The Washington Group has developed a short set of questions aimed at overcoming the distorting effect of many of the more traditional methods of categorising disability. The questions are intended to identify people in the population who are *“at greater risk than the general population of experiencing limited or restricted participation in society”* [Washington Group on Disability Statistics, 2009, “Understanding and Interpreting Disability as Measured using the WG Short Set of Questions”].

The questions devised by the Washington Group cover 6 key areas of functioning: vision, hearing, mobility, cognition, self-care and communication and capture the degree or severity of difficulty in each case.

The Report describes the change in data obtained by using this method in Zambia. The questions used in the 2000 Census to capture disability were: “Are you disabled in any way?” (Yes/No), and “What is your disability?” This approach gave a disability prevalence rate in Zambia of 2.7 per cent which represented a trebling of the 1990 population prevalence rate of 0.9 per cent which used the same approach but included only 4 impairment categories.

Using the Washington Group short set of questions in a 2006 Living Conditions Survey in Zambia a disability prevalence rate of 14.5 per cent was obtained.

Asking appropriate questions on a common basis is clearly a significant step forward, but as the Washington group notes the word “disability” often carries with it negative connotations and people may feel stigma or shame at self-identifying as disabled. For this reason, the question *Do you have a disability?* is considered inadequate at identifying, for example, mental or psychological impairments which

tend to be particularly stigmatising. People in some cultures may deny their disability or hide the fact that they have a disabled family member. “Disability” often also implies a very significant condition. People who can walk around their homes but are incapable of walking to market may not think of themselves as having a disability even though their daily activities are limited. This whole issue of cultural differences and personal perceptions of ability or disability underline the importance of asking the right questions in the right way.

The World Health Organisation’s International Classification of Functioning Disability and Health (ICF) [WHO, International Classification of Functioning Disability and Health, 2001] includes definitions of “*limitations on participation*” and “*limitations on activity*” as well as a specific domain dealing with “*mobility*” which includes a range of fields from walking to driving and using public transport.

STATISTICS AS A TOOL FOR POLICY AND ADVOCACY

WHO advocates the use of the ICF as “*a powerful tool for evidence based advocacy. It provides reliable and comparable data to make the case for change. The political notion that disability is as much the result of environmental barriers as it is of health conditions or impairments must be transformed, first into a research agenda and then into valid and reliable evidence. This evidence can bring genuine social change for persons with disabilities around the world*”.

The Washington Group goes on to argue that statistics are only of value to policy making if the numbers enable solutions to be targeted correctly at those who need them.

There is, however, a bigger issue that is particularly relevant to transport. The smaller the sub-sets of disability are revealed to be, the less likely it is that economists and politicians will see the justification in investment to solve those problems.

One example from the UK in the early 1990s illustrates the point. There was at that time a strong lobby from people with disabilities to replace conventional high floor buses with low floor buses equipped with ramps. The UK bus industry was largely privatised and profit driven and there was little interest in investing large sums of money for what were seen (correctly) as a very small minority of the population who used wheelchairs. The argument went on that, in any case, very few wheelchair users would choose to travel by bus even if the vehicles were accessible.

The breakthrough came from a Government sponsored trial in which operators were offered, on free loan, a low floor bus to try out on routes that they would normally operate with high floor vehicles. Predictably, there were virtually no wheelchair users sitting eagerly at the bus stop in those early days, but there were large numbers of people travelling with baby buggies (strollers) who had not traditionally been able to access the buses and were now choosing to travel on a regular basis. This meant that the economic case for low floor buses was made quickly and for many years now in the UK as in most of the rest of Europe they have been the norm.

Essentially this was an early example of the principle of universal design with a focus on providing a solution that benefitted everybody.

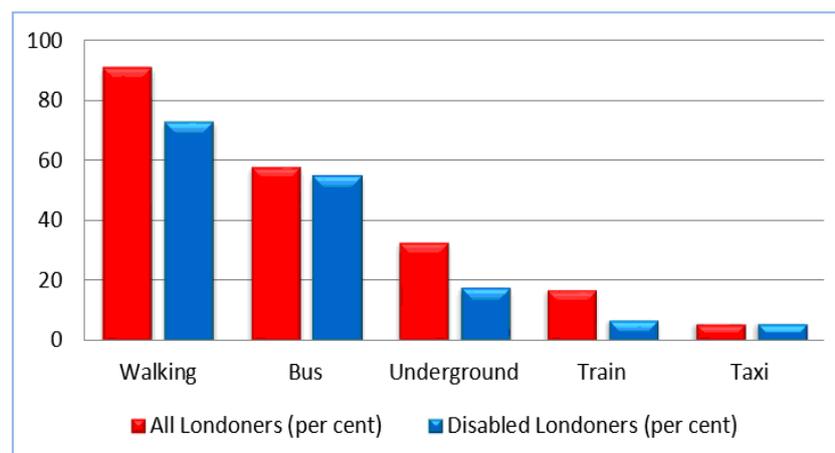
There are, however, other areas in which a clear and realistic picture of the numbers of people whose daily lives are impeded or restricted is a valuable catalyst for change. The argument is clearly more persuasive politically and economically in countries which provide a system of social care to support those who cannot live or function independently. The costs of bringing care into the home will in many cases greatly outweigh the costs of removing barriers to accessibility.

One simple example is the state of pavements (sidewalks) in many countries. If older people or people with disabilities cannot get from their homes to do even the most basic of local activities such as shopping for food because they cannot physically cope with broken and uneven paving or because they are frightened of fast moving traffic, the economic costs as well as the costs in terms of quality of life are considerable.

Lack of access to basic outdoor mobility and to local public transport plays a major part in sustaining the link between disability and poverty. Without the ability to travel, the chances of finding or keeping employment, or continuing in education are very limited indeed. Here too there is no clear picture of how many people are prevented from finding employment because of transport systems and local streets that create barriers to mobility. It is often easier to assume that people with disabilities are not in employment because they would be unreliable workers – even though there is clear evidence that disproves this. In India, for example, the employment rate of people with disabilities is 60 percent lower than that of the general population.

Mainstreaming the collection of disability data so that it is directly comparable with broader population data is particular useful in a transport context. In the example in Figure 2 below, Transport for London regularly gathers data about the total number of Londoners using specific transport modes compared with the numbers of disabled Londoners using the same modes.

Figure 1. Travel patterns of disabled persons in London, UK (the percentages of Londoners using a given mode of transport at least once a week)



Source: Transport for London "Perceptions of Public Transport in London among Equality & Inclusion Groups" 2007

Data of this kind makes it possible to see immediately where barriers to mobility are successfully being tackled and where further work is needed.

Sometimes, micro level analysis and data gathering can be more effective than a broad brush assessment. One example comes from Shanghai where a World Bank funded project engaged older people and people with disabilities in auditing the city themselves and reporting problems to city authorities. The project set out to establish the issues that were of greatest concern to people in the city, to prioritise problems and engage the public in delivering access improvements. This audit process is now repeated on an annual basis by the city authorities. It has helped to increase awareness of city authorities and contractors about the needs of disabled and older people, focus attention on the need for quality in the construction and maintenance processes and bring access improvements into the mainstream of city planning.

Another example comes from New Zealand [O'Fallon, C. (2010) *Auditing Public Transport Accessibility in New Zealand*, New Zealand Transport Agency, Research Report No 417, NZ Transport Agency, Wellington] where the Government commissioned an audit of urban public transport accessibility. This detailed study of a wide range of aspects of accessibility and how they affect different individuals and groups within the population has enabled the Government to identify shortcomings and gaps in current planning policies and how they impact on the goal of making public transport accessible. The route by route analysis identified that on one bus route served by a mix of accessible low-floor vehicles and older vehicles there were 25 bus stops at which part of the pedestrian route to the stop was not accessible, making it impossible for wheelchair users and other severely disabled people to use the bus.

Tourism is also an increasingly powerful economic driver and the potential market among tourists with disabilities is beginning to impact the thinking of some countries where accessibility had not previously been considered as a priority issue.

A report to the Caribbean Tourism Organisation from the Barbados Council for Disabled people [Caribbean 360 (2010) 'Disabled people a growing tourism market'] noted that: *'Collectively 75 per cent of Canadians, Americans & Europeans with disabilities who are physically and financially able to travel do so with their caregivers, family and friends. The current economic climate dictates that we target this emerging market.'*

The examples given above of targeted and sector specific gathering of data can be a much more effective policy tool than the traditional national census data simply because it can delve into much more detail and be more current. The time lag between national censuses and the often long delay in publishing data from them are both negative points in the context of transport planning.

The World Health Organisation (WHO) reports [WHO World Report on Disability 2011] that there is a correlation between the type of statistical collection done and the rate of disability. Those countries using large scale censuses are more likely to report low levels of disability than those using targeted surveys and applying a measurement approach that records activity limitations and participation restrictions.

For example, if pain is included as a measurement, unsurprisingly, the numbers of people recording difficulty in certain activities will increase significantly.

National level censuses are, nonetheless very valuable in building up an overall picture and in tracking trends over time.

Countries are increasingly moving towards a continuum approach to measurement where estimates of prevalence of disability and functioning are drawn from assessments made across a range of different activities and life functions. Critical differences can still occur depending on the extent to which environmental influences are taken into account.

CONCLUSIONS

It is clear that the way that statistics are gathered and used can have a profound effect on the life chances of people with disabilities. It is however essential that data continues to be gathered so that resources can be targeted and policies and practices adjusted to meet changing needs.

The global recognition of the demographic trends and the significant growth in the numbers of older people is one clear example of a wakeup call that has been heeded (albeit rather late in many cases) by politicians and policy makers. The sheer numbers of older people have made a strong impact on thinking and actions to deal with the policy and practical implications are now being put in place.

Where we still see national censuses indicating absurdly low levels of disability because the wrong questions have been asked, we will continue to see neglect at the political level of issues that are seen as insignificant. More widespread adoption of the classifications suggested by the ICF or the Washington Group will certainly help but will inevitably take a very long time to make an impact in many countries in the developing world.

In any event, although there is clearly benefit from large scale long term studies at national and international level, the data they generate is often too late or too broad ranging to be of use in planning and delivering improvements in transport services and the built environment.

In this context, local “micro” surveys involving people with disabilities in gathering the data and determining the policy are likely to be much more effective as drivers of change.

Paradoxically, at the other end of the spectrum the adoption of policies of universal design are another effective tool for addressing real need at street level. The policy

that everyone benefits from barrier free, intuitive design is one that does not depend on knowing how many people with what kind of disability may benefit, they will simply be part of the mainstream for whom the barriers have been removed.

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