

Disability as a Systems Probe for Evaluating Equity in Healthcare

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Abstract

A systems probe assesses specific activities which are dependent on a well functioning health system. Health services are a critical component of a broader health system which is interdependent on other sectors, such as education, employment and transport. People with disabilities constitute a significant challenge and a valuable probe of the effectiveness of health services and health systems, in terms of equity, accessibility and right to health. By considering health indicators for people with disabilities in combination with measures of activity limitations and access to services, we can probe the overall effectiveness of the health system provided to the wider community.

Introduction

It has been argued that “maternal mortality is a key indicator of a country's progress in improving health”¹ and may therefore be a good metric for probing the effectiveness of health service provision. The idea of such a probe is that while it assesses a particular aspect of health services, that aspect is in fact dependent on the efficient working of much broader systemic factors. Thus while a systems probe may be focused on relatively specific activities, those activities are in turn dependent on other activities. We propose that the provision of health care to persons with disabilities constitutes a good probe, not just of health service provision, but, importantly, of the effectiveness of the overall health system, including the other services on which access to equitable healthcare depends. By measuring how well the health needs of persons with disability are being addressed we can get a good idea of the responsiveness of the health system to the health needs of the overall population.

Disability and Research for Health

“Disabled people have the same needs for basic health services as everyone else. This is often denied”². With an estimated 650 million people living with disabilities in the world today and 2 billion family members directly affected by disability³, persons with disability represent a significant and largely overlooked challenge. However, it is now recognised that we cannot achieve the Millennium Development Goals without addressing their health needs and rights. Addressing the rights to health for persons with disabilities may bring benefits to everyone because it explicitly also presents us with the challenge of addressing the inter-sectoral nature of health – exactly what is called for in the *Bamako Call to Action on Research for Health*³ issued at the conclusion of the 2008 Global Health Ministerial Summit in Mali.

The International Classification of Function, Disability and Health (ICF⁴) was endorsed by 191 World Health Organization Member States in the Fifty-fourth World Health Assembly in 2001. It sees ‘disability’ as having a degree of functional *impairment(s)* involving an organ or body part, which possibly results in *activity limitation(s)* such as difficulties executing tasks or activities of daily living, and also possibly leading to *participation restrictions*, where a person is less able to play a meaningful role in society. This understanding of disability is much broader than the traditional concept of disability as an intrinsic ‘handicap’ which you either have or you don’t, such as amputation or spinal cord injury. Instead it also incorporates many types of chronic illness, and more transitory conditions that impair functioning, limit activities or restrict participation. Everyone can therefore expect to experience some degree of disability at some point in their life. However, to develop further the potential of using the experiences of persons with disabilities as a probe to assess overall health systems functioning we must have reliable and valid measures of both disability and accessibility.

Equity, Disability & Accessibility

Equity in health “implies that ideally everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that no one should be disadvantaged from achieving this potential, if it can be avoided”⁵, Pg 433 Equity in healthcare implies “equal access to available care for equal need, equal utilization for equal need, equal quality of care for all”⁵, Pg 434 A review of concepts and measurements of equity found the above definitions to be “clear and accessible to non-technical audiences, but lacking guidance on measurement”⁶ Combining measures of disability and accessibility can contribute to solving this problem.

International research projects such as Measuring Health and Disability in Europe⁷ and the Washington City Group on Disability Statistics⁸ have advanced measurement techniques, using the continuum of *activity limitations* as the most feasible dimension to accurately measure in self-report and observational studies (Washington City Group on Disability Statistics⁹, EUROSTAT¹⁰ and Budapest Initiative¹¹). Measures developed by these initiatives are now being used in general household surveys, national censuses, as well as in specialized health surveys. Combining these initiatives with measures of access to health care could be a way forward in documenting equity in healthcare.

We propose that a measure of *access to health services* could utilize the conceptual framework offered in the General Comment of the United Nations Committee on Economic, Social and Cultural Rights (2000)¹² Aspects of that framework include *Accessibility*, which refers to the need for facilities, goods and services to be accessible to everyone without discrimination, and within the jurisdiction of the State. *Accessibility* has been further broken down into the related dimensions of Non-discrimination; Physical Accessibility; Economic Accessibility (affordability) and Information Accessibility. There are however additional aspects of the General Comment that also relate to the concept of accessibility. *Availability*, concerns the quantity of service available; so for instance functioning public health and health-care facilities, goods and services, as well as programmes, have to be available to the general public in sufficient quantity. A further aspect, *Acceptability*, stresses that all health facilities, goods and services must be respectful of medical ethics, be culturally appropriate, sensitive to gender and life-cycle

requirements, as well as designed to respect confidentiality and improve the health status of those concerned. The final aspect refers to *Quality*, so for instance health facilities, goods and services must be scientifically and medically appropriate to provide services of good quality.

Thus *combining* measures of *activity limitations* and *access to health services* could provide a metric for evaluating equity in healthcare. The best way of ‘stress testing’ health systems in this regard would be to evaluate the experiences of those people for whom activity limitations and access may be most challenging, and they are, of course, persons with disabilities.

Assessing Systems not Services

Activity limitations, whether they arise from spinal cord injury, diabetes or HIV/AIDS, may constitute a significant barrier to accessing healthcare. Transport to healthcare facilities may be inaccessible, education non-inclusive or social welfare supports insufficient, to allow access to healthcare. The Bamako Call stresses, “research for health” (rather than ‘health research’) recognising this critical interdependency of health services and other service provision, in order to be able to provide ‘health for all’. The ‘system’ that facilitates health thus reaches far beyond the confines of health facilities and health professionals. And the predicament of persons with disabilities makes them more vulnerable to the consequences of failings in any one aspect of the – ideally – interconnecting system.

Objective *indicators* of health service coverage (e.g. immunization rates) and disease incidence (e.g. STD infection) can be *combined* with indicators for specific provisions (e.g. prosthetic devices), experiential indicators (e.g. users’ reports of staff attitudes) and measures of activity limitations and accessibility as described above. Such a composite of indicators can be used to assess the overall effectiveness of health systems, either by trying to get all service users to complete them, or by focusing on certain groups whose service needs may be particularly informative regarding overall systems functioning. While the use of maternal healthcare has been advocated for this purpose, this suggestion relates more specifically to the provision of actual services, rather than incorporating the broader inter-sectoral context on which such services are dependent. With the possibility of measuring both activity limitations and accessibility, we suggest that exploring the experiences of persons with disabilities may present an ideal way of probing the efficacy of inter-sectoral aspects of health systems. We therefore call for more research focusing on disability as a systems probe for evaluating equity in healthcare.

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