

Disability certificates in India: a challenge to health privacy

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Abstract

A "disability certificate" is necessary to access benefits afforded under the Persons with Disabilities Act (1995) in India. This paper analyses this requirement and concludes that it constitutes a major challenge to maintaining privacy of health information especially for persons with mental health disabilities in India and recommends modifications in the certificate's format and use, to reduce the magnitude of privacy infringement for those using the disability certificate to access benefits to which they are legally entitled.

Background on disability in India

Disability can be painful and burdensome for individuals and may present special challenges for their families. When employing social and political tools to address these burdens, it may best be conceived according to a "social model" (1), whereby disability results from the relationship or "fit" between an individual's abilities and the social as well as physical environment in which she lives (2). Every society must attempt to address the disabilities of its members in a way that respects the autonomy and human rights of disabled people and allows them to pursue a satisfying quality of life. Yet, each country must address the disabilities of its residents according to its strengths or capacity. Indeed, conditions that are disabling in one society may not be so, or not to the same degree, in another because of cultural and local differences (e.g., physical disabilities in a rural context may not be so restrictive in an urban setting with ample resources). Moreover, different societies have different levels of resources available to help individuals compensate for or accommodate disability.

In India, the 2001 census identified 21.9 million people with disabilities, though the number has been estimated to be as high as 70 million (3, 4). One social provision intended to alleviate the burden of disability for these individuals is the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995 [PWD Act] (5). According to the Act, disability includes blindness, low vision, cured leprosy, hearing impairment, locomotor disability, mental retardation, and mental illness. The PWD Act constitutes an important step towards enabling the disabled in India. Based on the provisions of the Act those who are 40 per cent disabled, as certified by a governmental medical authority, are entitled to receive particular benefits from the government of India (Gol). A certain percentage of government jobs, for example, is reserved for those with certified disabilities. Educational institutions that receive aid from the Gol must reserve at least three per cent of their seats for persons with disabilities. Travel

concessions and tax rebates are also available for the disabled and their escorts or caregivers.

Impact of disability certificates on privacy and welfare

Despite the advantages it affords, the Act also presents a challenge for the disabled in another area of their health and rights—namely, the protection of their privacy. These privacy concerns arise because of the way the Act is implemented and what individuals must do in order to qualify for benefits under its provisions. Specifically, individuals seeking benefits must obtain a disability certificate from a specified government healthcare provider. The certificate itself needs to display a photograph (certified by due authority), as well as the name and address of the individual, which can increase the risk of confidentiality breach should the certificate be misplaced or stolen, or merely viewed by unauthorised persons. Further, the certificate details not only the diagnosis, but also the duration of illness and degree of disability.

The effective utilisation of the various provisions of this Act plays an integral part in ultimate socio-economic benefits that disabled individuals may obtain (4), and yet many who would qualify for these benefits are prevented by their disability from obtaining the disability certificate without assistance. Therefore, it is necessary that family members or caretakers of the affected individuals help them obtain a disability certificate. This need for assistance requires that the disabled person share information that she or he might prefer to keep private. While some disabilities are readily apparent and cannot be kept from others, some disabilities could be kept largely private. Obsessive compulsive disorder, depression, and many other mental illnesses, for example, are not as readily apparent as impairments of sight or mobility. Nevertheless, those with such disorders may need assistance in obtaining a disability certificate, perhaps because their disorder prevents them from being sufficiently motivated to apply for benefits on their own. Other mental illnesses may be cognitively impairing so that a person cannot, at least at some times, complete the tasks of applying for a certificate. Symptoms of paranoia might prevent a mentally ill person from approaching a doctor for certification and then subsequently approaching a government office for specific benefits. So, even to apply for a disability certificate, some disabled individuals will have to suffer the invasion of privacy of their health information by sharing the information with a family member or other interested party.

Of course, this is not the only context in which individuals with health conditions must disclose private information in order to

seek help. Patients do this when they seek healthcare at a clinic or from a physician. Healthcare professionals are then ethically and legally obligated to keep such information confidential both to respect patients' privacy and autonomy and to protect them from possible harms that could result from the disclosure of private health information. In order for healthcare delivery to be effective, patients must feel comfortable disclosing private information to professionals without fear of social or economic repercussions, embarrassment, or stigma (6).

Similarly, people with illnesses and disabilities are often dependent on family or nonprofessional caregivers for assistance and care. They must share private information—e.g., about their condition, bodily functions, and needs—with these nonprofessionals in order to receive help, sometimes including help with activities of daily living. While family members and nonprofessional caregivers do not have legal duties to respect the privacy of their charges, and certainly do not have a professional code of ethics that mandates respect for privacy, they do have ethical obligations to respect the privacy of those they love or provide care for (7). So, the unavoidable need to disclose a disability to a family member in order to receive help in applying for a disability certificate may not be that different from asking family members for aid in going to the doctor, taking medicine, or accomplishing daily tasks. Ideally, family members then assume the ethical obligation to respect their relative's privacy and keep her health information confidential. Moreover, family members may have an interest in safeguarding information about non-obvious disabilities that are present in their family, because of concerns about stigma and discrimination that attach to such conditions, especially as the familial and genetic aspects of some conditions become better understood.

Regarding the disability certificate, however, what is a distinctive and largely avoidable invasion of privacy is the subsequent use of the certificate, once it is obtained. Currently, the disability certificate must be presented in government and private offices to receive a variety of concession certificates or tax benefits. The concession certificate, in turn, must be presented to a variety of non-health professionals in order to obtain benefits. The ticket clerk at any Indian railway station, for example, must be presented the concession certificate in order to obtain a discounted ticket or monthly pass.

Each of these documents—e.g., the travel concession certificate and ticket itself—unnecessarily documents the nature of the disability and links the person's name and disability on a form that may go astray and that is certainly viewed by people who are not bound by any regulation or code of ethics to keep the person's health information confidential. For individuals with less obvious disabilities—e.g., mental illness or retardation, or cured leprosy that leaves no obvious disfigurement—it is seeking the benefits to which the PWD Act entitles them that exposes them to the greatest risks of stigma and discrimination. Because mental illness and mental retardation (and leprosy) are highly stigmatising (8), individuals with these conditions may justifiably have some hesitation in using the certificate to seek

benefits to which they are entitled. Further, the certification of the mentally ill person may not only stigmatise the patient, but also his family members. The labeling of the person can affect marriage prospects of family members (especially female siblings and offspring), as well as business opportunities and access to private health or life insurance for family members.

Moreover, other agencies—e.g., the railway ministry—issue certificates affording concessions for a wider range of disabilities than those covered by the PWD Act. A person with cancer, for example, may receive a discounted railway fare. Yet the price to be paid for this otherwise valuable and well-intentioned benefit is exposure of her cancer condition, something that could otherwise be kept largely private beyond her immediate family and healthcare settings. In some cases, even the train ticket itself will state the cancer diagnosis. While cancer may now be less stigmatising than mental illness or leprosy, some people still retain erroneous beliefs that cancer is contagious or that having cancer is a reflection of a person's character. Thus revelation of one's cancer diagnosis to a ticket checker or fellow passenger can be stigmatising and lead to social shunning as well as more official forms of discrimination.

Recommendations to increase privacy protection while maintaining safeguards against fraud

The unnecessarily cumbersome and humiliating process of declaring the nature of one's disability in multiple documents at multiple offices should be streamlined to protect individuals' privacy as much as possible. Furthermore, it is unnecessary to state the nature of the individual's disability on each of these documents. The process for obtaining and using a disability certificate to avail of legally provided benefits should be revised.

Both the union and state governments issue guidelines regarding issue of disability certificates. At present, certification of a person's disability for purposes of receiving benefits under the PWD Act, 1995, is only obtainable from designated physicians at government facilities. While only doctors with seniority and experience, and only government hospitals with requisite facilities at the district level and above, can issue certificates, concerns may be raised about the possibility of physicians issuing erroneous or even fraudulent disability certificates to persons without a qualifying disability.

At present, very little is taught about disability and disability certification at the post graduate level in India. Training regarding the disability certification process should be a mandatory component of a doctors' curriculum, and hospitals should offer continuing education to maintain an up-to-date understanding of the process and regulations among doctors. Such training would serve to reduce error. Intentional fraud may be more difficult to address.

Disability certificates are issued only by designated doctors using a prescribed form, and a doctor who signs these certificates must include his Medical Council registration number. This measure is designed to ensure accountability

and minimise the potential for fraudulent certificates to be issued. Two additional measures could enhance these preventive measures. First, it could be required that all disability certificates be crosschecked by a second doctor of the same institution so that a single individual cannot wrongly issue disability certificates without being detected. Disputes between those physicians would be resolved by a designated hospital administrator. Ideally, this would be the same hospital administrator who countersigns the certificate. Doctors who are repeatedly found to be issuing certificates in "error" (inadvertently or intentionally) could be required to complete training on the certification of disability and penalised, if necessary. If their inappropriate issuing of certificates continued, they could be penalised by the hospital administration, as their error or fraud places the institution itself at risk of accusations of fraud. Moreover, when certification of disability is undertaken, patients and their family members should be informed, and required to acknowledge that they are legally responsible for any misrepresentation or misinformation they offer regarding the disability.

Second, the directorate general of health services, the agency responsible for implementation of the disability certificate provision of the Disability Act, 1995, could institute a process of auditing institutions for the appropriateness of their issuing of disability certificates. Records of the issue of certificates should be retained by the hospital and made available for periodic audit, which would involve review of the medical record, including laboratory test results, history and physical notes, or results of assessment questionnaires developed to assess the duration and type of symptoms and degree of impairment, in the case of mental disability. Details of such an audit process would need to be developed by the office of the directorate general.

It may be thought that the greatest threat of fraud occurs not at the level of doctors certifying disability and issuing a disability certificate, but subsequently when perhaps fraudulent (fake) documents are presented in government or private offices to receive a concession certificate or tax benefit, or later, when the concession certificate is presented for the particular benefit, such as a discounted train ticket. Linking the certificate, the bearer's photo, and a description of the disability may be considered necessary in order to prevent fraud at this level. In effect, those issuing concessions or checking train tickets are turned into agents of fraud prevention by asking them to verify that the person in front of them is truly disabled. But railway employees, for example, are not qualified to assess whether the person before them truly has cancer or mental illness; therefore, requiring production of a statement describing the nature of the disability at these levels is not warranted. At most, they should be required to verify identity by matching names on documents or matching a photo on a document to the person presenting herself.

A revised, more appropriate process—respectful of privacy and mindful of risk of fraud—would proceed in the following manner. Upon presentation of the initial medical certification of disability, and verification of her identity, the individual should be issued a document stating the concessions or benefits for which she is qualified without any further detail about the nature of her condition. Such a document regarding concessions might bear the individual's photograph if identification of the document holder is necessary to prevent fraud (and no other form of photo identification is available and reliable). However, following certification of disability, the nature of the disability need not be publicly linked with the document, photo, or individual. Further, there is no need for a travel ticket, for example, to state the nature of the individual's condition. There should be no requirement that the individual carry with her a copy of her initial certification of disability or that she supply it upon demand to government workers and ticket checkers throughout her daily life. This is an unnecessary ordeal that presents multiple daily breaches of privacy for those whose disabilities could otherwise be kept more private. Preservation of such privacy is an individual's right as a matter of respect for her autonomy. It is also critically important in order to avoid stigma, discrimination, and other negative social, economic, and psychological consequences (6).

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