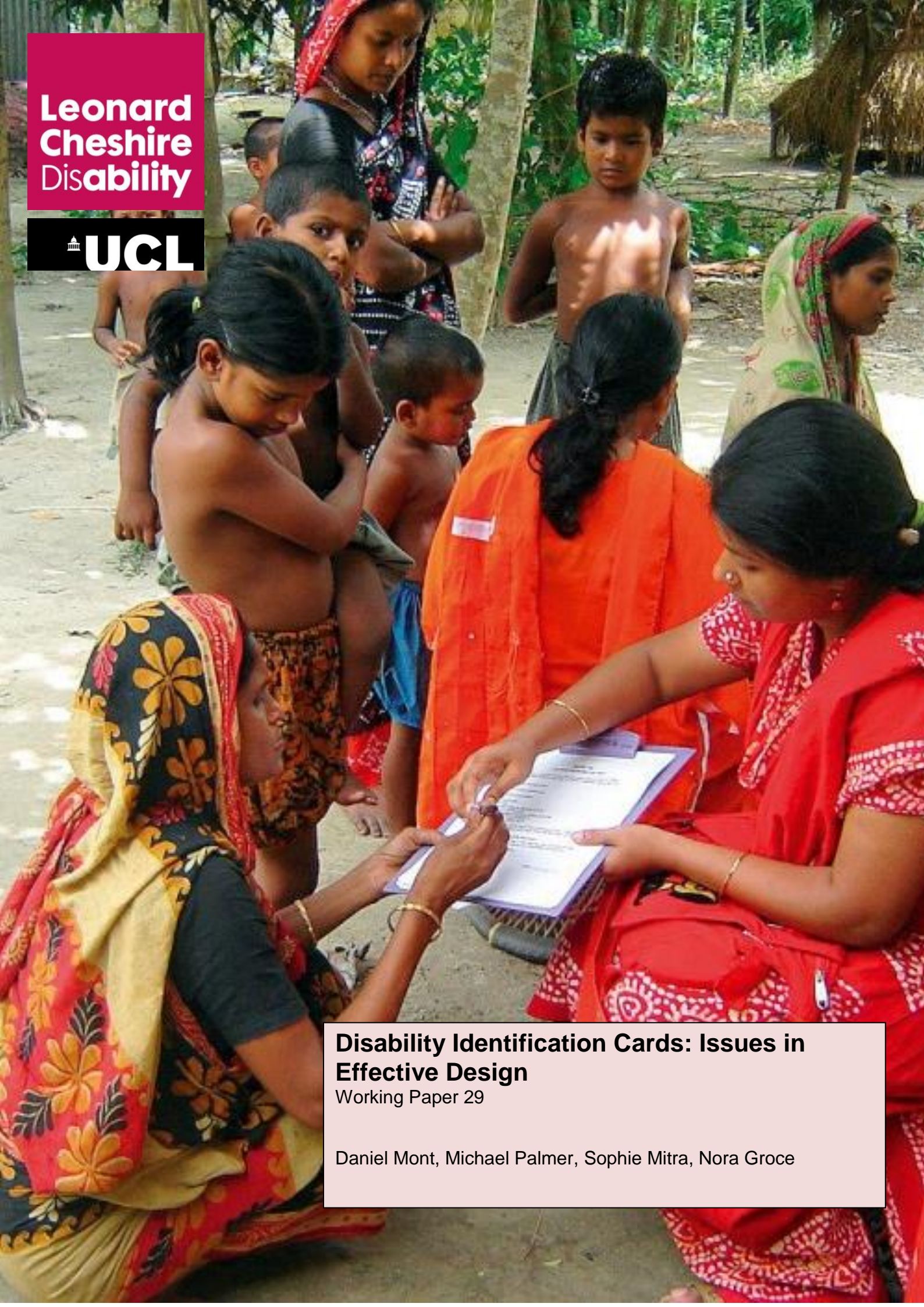




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## Disability Identification Cards: Issues in Effective Design

Working Paper 29

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# Leonard Cheshire Disability and Inclusive Development Centre

## Disability Identification Cards: Issues in Effective Design

2016

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### Working Paper Series: No. 29

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## **Abstract**

Around the world, attention to the issue of disability inclusion is gaining increasing prominence. One strategy to promote disability-inclusion in benefit participation programs that a growing number of countries are considering is the creation of a disability identification (ID) card. There exists a long history of various types of disability ID cards (or certificates) and associated social protection schemes in high-income countries. Disability ID cards currently exist in many middle-income countries, and are under development or consideration in a growing number of low and middle-income countries. However, it should be acknowledged that many of the issues with respect to the administration of a disability ID card in low and middle-income countries differ from those in high-income countries. The purpose of this article is to discuss some of the challenges involved in creating a disability ID and identify key issues that can help in developing a framework for addressing these challenges in the context of low and middle-income countries. We argue that countries considering instituting disability ID cards must move with caution; ID card programs can only advance disability policy and the wellbeing of persons with disabilities if undertaken in well-designed manner in line with a country's administrative capacity.

**Key Words:** Disability ID cards, low and middle-income countries, social protection, disability benefits

## **Introduction**

Around the world, attention to the issue of disability is gaining increasing prominence. Global efforts such as the Convention of the Rights of Persons with Disabilities (CRPD), as well as regional initiatives such as the Incheon “Make the Right Real” Strategy, call for the recognition of the rights of people with disabilities in regards to all facets of economic and social life. As a result, more and more countries are turning to providing specific benefits to people with disabilities. This coincides with a “quantum leap” in the development and adoption of general social protection programmes as countries have begun emerging from low and middle-income status. (Laiglesia, 2011)

One strategy to promote disability-inclusion in benefit programs that a growing number of countries are considering is the creation of a disability identification (ID) card.

The justification for such a card can be fourfold. First, people with disabilities often have additional needs and/or face additional costs that are not incorporated into regular social protection programs - for example, the need for assistive devices and personal assistance. Cards can be used to signify eligibility to these special benefits. Second, people with disabilities are often discriminated against. In cases where anti-discrimination laws exist, people must be recognized as a member of the class of people with disabilities to have legal standing to initiate enforcement procedures. Cards can be used to signify this, as well. Third, in practice, programs may not adequately secure the rights of people with disabilities in regards to social and economic participation even when they purport to be inclusive. The issuing of such a card in effect is a political statement by the government that it officially recognizes the government’s responsibility to address the rights and needs of persons with disabilities, and thus can be used as an advocacy lever for improving and expanding the rights and services attached to the card. And finally, card systems can also serve as an administrative data collection system to improve policies related to inclusion and disability such as in Thailand, where in addition to information needed for the

eligibility determination, data is collected on the needs of persons with disability in order to better inform public policy.

There exists a long history of various types of disability ID cards (or certificates) and associated social protection schemes in high-income countries. Typically, such cards are used to certify eligibility for various disability specific social protection programs. Disability ID cards currently exist in many middle-income countries (e.g., Ecuador, Nepal, Philippines, Thailand), and are now under development or consideration in a number of low and middle-income countries (e.g. Cambodia, Haiti, India, Vietnam). It is important to acknowledge that many of the issues and concerns with respect to the administration of a disability ID card in low and middle-income countries differ from those in high-income countries. ID cards are relevant for countries with established benefit programs or laws that apply to persons with disabilities. However, this article argues that countries must move with caution, for a poorly run and poorly funded system could waste limited resources and in a worst-case scenario, actually disenfranchise some people with disabilities who legitimately would benefit from state support.

The purpose of this article is to discuss some of the challenges involved in creating a disability ID and identify key issues that can help in developing a framework for addressing these challenges in the context of low and middle-income countries.

### **Purpose of the Card**

The purpose of disability ID cards can be either for direct economic security and poverty alleviation (e.g., social assistance and health care provision) or to promote an enabling environment and equalization of opportunities (e.g., anti-discrimination legislation, inclusive education, vocational training; Palmer, 2012). The purpose of the card will be directly linked to the issue of who is eligible to receive its benefits. Of course, a card may have multiple benefits with different eligibility criteria such as in Nepal where four color-coded levels determine different grade of benefits depending upon the severity of the disability. (Nepal Disabled Women's Association, 2013)

Economic security benefits are commonly provided to address income deprivation experienced by families with disability as a result of reduced earning capacity of the person with a disability or their primary caregiver in the household. Benefits regularly include variations of income support such as a monthly income allowance, carer allowances, and public transport subsidies or waivers.

Typically, benefits are limited to people whose disability restricts the type of work that they can do – and this is taken as a proxy for disability severity, and/or for identifying persons that qualify as living in conditions of poverty. Other economic security benefits are designed to cover the additional costs associated with disability such as health care, medication, rehabilitation, assistive devices transportation and personal caregiving. (Mitra, Posarac, & Vick, 2013). Such benefits may not be linked to work or poverty status. However, persons will have to meet a certain disability threshold defined by eligibility determination guidelines. In the Philippines, for example, there exists a program to provide a 20% discount for selected items for anyone holding a disability ID card, regardless of work status. Similarly, entitlements to benefits, which are intended to promote an enabling environment, such as inclusive education and vocational training, will be determined by an assessment of needs.

As stated above, another reason for ID cards is for identifying a person with a disability and recognizing their membership in a protected class. Under a disability rights law, a person with a disability may have the right to sue an entity that has discriminated against them. In order to have legal standing to bring such a suit the person must be recognized as having a disability. This person may not be eligible for a country's disability social protection program (e.g. if it is only a means tested program and they are working full time). This determination could be made on a case-by-case basis in court, but it could save the plaintiff's time and money if the government has already certified the person as having that standing. For instance, in Thailand the disability ID card automatically qualifies someone as being able to file a discrimination complaint. If someone without a card files a complaint, that complaint

will be accepted on a provisional basis until the person is determined to be eligible for the disability card.

### **Disability determination**

Generally speaking, countries have relied primarily on a medical model for determining the eligibility for disability ID programs. That is, if a person has a particular medical condition as verified by a health professional, then they qualify as having a disability. Countries also often allow people without those particular conditions to qualify for benefits if they have functional restrictions linked to some health condition that is generally linked to the inability to work (e.g. United States, United Kingdom). Even when examining functional limitations, though, there must always be a documented link to a medical condition. This is usually deemed essential in order to both expedite the process and reduce the potential for fraud

Technically, reliance on medical conditions is at odds with the CRPD, which calls for the use of the social model of disability, and which recognizes disability as emerging from the interaction of a person's impairments with attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. Conceivably, some people who would be defined as having a disability under the CRPD social/human rights model of disability would not qualify for a disability ID card under a medical model, even if supplemented by a test to consider a person's ability to work.

Exclusive reliance on medical conditions ignores the fact that people with the same condition may be very different from one another when it comes to disability, depending on where they live and work, even within the same country. For example, a person with some difficulty walking may face minimal barriers to participation in society in the capital city but profound barriers in a remote region with a rough topography and poor infrastructure. A one-size-fits-all determination procedure could either wrongfully include some or exclude others.

Of course, if the nature of the benefits being provided are purely medical in nature -- for example access to health care or particular rehabilitation services -- then a medical determination could be appropriate. However, if the aim of the benefits associated with the card is to provide a broader support to help secure the rights of people with disabilities and enhance social and economic participation, then a social model approach seems more relevant.

## **Administration**

A key issue in ID programs is who is responsible for the determination of disability. Is it a medical professional, a local community worker, a community board? Are these people properly and uniformly trained in how to make determinations? There are several models but to a large extent, it depends on the nature of the eligibility procedure. For example, in the United States there is an initial medical assessment to certify that the person has a condition that impacts his or her ability to function, but a government worker with special training undertakes the eligibility determination, including a functional assessment. However, training and retaining administrators to oversee this process can add a further complication to disability ID systems. For example, due to the large number of applications and complicated demands of the assessment procedure, the overall attrition rate for examiners is about 13 percent annually, and the US Social Security Administration claims the training for examiners can take more than two years. The complexity of the determination is primarily tied to the fact that the certification is for work disability. Determinations are less complicated if not tied to the ability to work.

Another strategy is to have a community board make the determination, with possibly an appeal system to government or medical experts if a person is refused. A local community worker or community board makes a determination about a person's ability to undertake basic activities (walking, self-care, going to the market, etc.) in the local environment. The community based model is better placed to assess the living standards and access to production related activities if poverty status is an eligibility criterion. In the Vietnam system, for example, initial eligibility



determinations are made at the commune council level. However, even such a system based on the ability to do basic activities usually needs some sort of medical or official certification as an entry into the determination process to prevent fraud.

Another approach is to create a rubric based on the International Classification of Functioning, Disability and Health (ICF) or on medical diagnoses. The ICF is a detailed classification system for recording a person's ability to function at three different levels: body function and structure, the ability to undertake basic activities (e.g., walking or seeing), and the ability to participate in society (e.g., working or going to school). With either an ICF or medical diagnosis approach, a community board would not be appropriate. Developing a determination procedure that draws directly upon the ICF poses a degree of administrative complexity that could require a fair amount of capacity building. As environments differ between countries, such a system would have to be adapted to the local context.

### **Miscellaneous Registration Issues**

It is important that the system for applying for an ID card be open to everyone who feels they have a disability. Public awareness programs are required to inform people about the program and the application procedures. Of course, in some countries, such as Vietnam and Cambodia, people are typically identified by the commune and do not apply on their own accord. In theory, people can self-nominate to be identified but in these countries, a large number of people do not know this. Therefore, the first requirement for a disability identification card is general awareness-raising of the existence of the card, its purpose, and how to apply for it. Naturally, information about the program and application procedures need to be in multiple formats so that people with vision, hearing, and cognitive impairments can learn about the program. Online applications should be on accessible websites and offline applications should be available in Braille. Allowance must also be made for people who are illiterate, especially since people with disabilities are more likely to be unable to read and write. If people need to get medical certifications then

assessment sites should be accessible (both physically and in terms of communication, such as sign language interpretation).

In terms of determining eligibility, the issue is not only the status of an individual's functional difficulties (or medical condition) at time of registration, but whether the person's disability status may change over time. Consideration could be given to the environmental context or access to assistance or assistive devices to assess the extent to which changes in these (for good or ill) affect eligibility for a card. For these reasons, another issue to consider at the time of issuance is whether eligibility for the card is permanent or if the person should be re-certified and on what schedule. For example, in South Africa, the Disability Grant is a non-contributory means tested program and benefits are granted on a temporary or permanent basis. The Temporary Program is only designed for those that have a disability that will prevent them from working for no less than six months and no more than one year.

In U.S. based programs for disability related to work injuries, a determination is made about Maximum Medical Improvement. If a condition is considered as qualifying for Maximum Medical Improvement and to be disabling, then the person qualifies for permanent instead of temporary benefits. Another consideration in setting up a system for disability ID cards is whether recipients need to have a permanent disability or a temporary, albeit, long term disability. If the disability is not considered permanent, then a review schedule must be set up to re-evaluate the person at a later date. While this would encourage future work and lessen expenditures, it would increase administrative complexity.

A final issue is that that disability determination procedure is difficult, and generally involves a fair amount of discretion. For that reason, it is important to have an appeals process in place to allow people denied the card another opportunity to secure one. In the United States, for example, roughly one-third of people now qualified for disability benefits receive those benefits upon appeal. An application procedure without an appeals process will invariably exclude people who should be receiving benefits.

## **Implications for Policy Development**

In light of the review of issues related to disability ID cards discussed above, we argue that caution is needed for the many countries that are considering establishing disability ID cards. Moving rapidly to implement a disability ID system before ironing out certain issues could create long term structural problems that increase the costs and reduce the efficiency of disability related programs and policies.

It is important to be very clear about the purpose of the ID card, and how it links to the benefits to be provided. One approach that many countries use when it comes to social protection for people with disabilities is to link benefits to the ability to work. This limits the population receiving the card and is intended to help only people with disabilities who cannot generate their own livelihood because of their disability status. One criticism of this approach is that it creates work disincentives by making people choose between trying to work and receiving benefits.

Another approach to providing disability benefits is to make their receipt independent of the ability to work. In this case, the benefits are conceived as helping to offset the extra costs of living with a disability that all people with a disability have; if they are still poor they can qualify for general social assistance available to all poor people. This second approach entails a broader definition of who has a disability. If a government has multiple reasons for establishing a disability ID system, then the card could be rated by degree of disability. In any case, the approach to card eligibility must be closely linked to the purpose of the card.

Secondly, it is important that the disability determination procedure align with the stated purpose of the card. To prevent fraud and to streamline certification for people with very clear conditions, a medical component is generally necessary. A person should have to document that they have a health condition that could potentially be disabling. If benefits are confined to medical interventions, this could be sufficient. However, if the goals of the programs are to promote and protect the rights of people with disability to participate in society then the determination procedure needs to reflect wider barriers to participation such as attitudinal and environmental barriers as specified in the CRPD.

Once the determination procedure is decided upon, the next question is how it should be administered. Should it be undertaken by medical or government experts, a community board, or some hybrid combination of both? If the approach taken is to determine a person's ability to undertake basic activities — e.g., shop in the market, prepare meals, manage the household — then it could be that a community board with appropriate tools could undertake such an evaluation. Of course the correlation between some conditions and disability might be so high that it makes administrative sense to make the condition itself grounds for eligibility. However, community based mechanisms may not be able to accurately identify and assess some medical conditions. For practical purposes, of course, the disability determination tool or procedure must align with administrative capacity. Moreover, it is important that the procedure be well publicized and accessible. An appeals procedure must be in place, as well as review procedures to assess the changing nature of disability over time.

ID card programs can only advance disability policy and the wellbeing of persons with disabilities if undertaken in well-designed manner in line with a country's administrative capacity, which in turn requires resources and political commitment on a sustainable basis. Each country needs to determine the most beneficial and least costly way of making its policies and programs disability-inclusive. This requires a strategic plan on how to move forward with both making general programs inclusive - that is, accessible to people with disabilities - as well as designing specific programs for people with disabilities that contain a well-designed eligibility procedure, possibly with the issuance of disability cards.

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