

Invisible lives

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Valorisation

This research concludes by highlighting the continued isolation and segregation experienced by persons with disabilities in rural India who live in a survival mode. They have no choice or control over their lives as a consequence of the complex interaction between different factors that may be either internal to their personality or external to their social, political, infrastructural environment. Therefore, improving their situation is not easy and it requires action in different domains by different actors. In this chapter, I provide some thoughts about the direction that could be taken by the government, non-governmental organisations and organisations of persons with disabilities, private businesses and rehabilitation professionals to improve the situation. These recommendations are based on the Indian perspective but also may be useful for other low and middle-income countries in Asia who face challenges in realising the rights of persons with disabilities.

The focus of this research is on the support services that are available to persons with disabilities to have autonomy in undertaking their daily living activities, which, according to the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), is a right of persons with disabilities. This means that countries who have ratified the UN CRPD are obliged to promote and provide support services to all its citizens with disabilities. An evaluation of the legislative frameworks relating to support services of four countries in Asia including India (chapter 2) reflected on some good examples that countries have taken in the direction of operationalising the UN CRPD. For instance:

- All the countries reviewed use a broad definition to define persons with disabilities. Such definitions are based on the UN CRPD and conceptualise disability as a social construct and focus on the barriers faced by a person with disabilities that result in their unequal participation. Such a focus requires looking at solutions for removing barriers and

providing the preconditions for the participation of persons with disabilities such as support services and accessibility.

- In Nepal, the classification of disabilities defines the eligibility to receive government aid for support services. This classification is based on the functioning of the person to undertake daily activities and participate in social activities. Therefore, eligibility to receive government-aided support services looks at wider aspects of the life of a person with disabilities and not just focus on the severity of impairment. However, the presence of additional eligibility criteria including poverty and the having a family limits access.
- According to the South Korean legislation all persons with disabilities are eligible to receive support services. They are means-tested to decide on the amount of aid they will receive from the government. Aid is in the form of vouchers that persons with disabilities can use to buy services from the provider of their choice. Such a model promotes the development of support services in the community and also offers choice and control to the service users. However, eligibility criteria to receive government aid focus on the severity of impairment and not on functioning.
- Indian legislation has introduced caregivers allowance as a social protection measure. While the allowance is poverty targeted and therefore few persons with disabilities can benefit from it, such an allowance recognises the time and effort spent in caregiving and is useful to compensate for it. However, legislation that looks at the family as the main caregiver can be restrictive to both the families and the persons with disabilities.
- The Philippines legislation has a provision of providing training to families to support and care for the disabled family member. Such training can equip the families to perform these responsibilities more efficiently and also have better outcomes of care and support for persons with disabilities. However, here again, it is presumed that only the family would provide care and support.

These are some concrete directions for support service provision that countries have adopted, but there is yet a lot to achieve. Support services in low and middle-income countries like India remain under-developed and inadequate. Therefore, legislative amendments are important to be undertaken that address support services as a 'right' that makes it a state's obligation to create a formal support services system in the country that gives persons with disabilities access to paid support.

Legislative amendments recommended

Legislation relating to support services may have two critical but interrelated directions. First, ensuring that all persons with disabilities are eligible to access support services. Second, creating a demand for formal support services in the country. Presently, the poverty targeted approach that the government has towards providing support services not only restricts the number of persons who have access to these services but also shrinks the demand for them dampening the chances for developing formal support services systems. The perceived role of the family as the main caregivers also reduces the chances of developing formal support services.

One way of tackling this situation is by reviewing the eligibility mechanism that the country follows. Restricting eligibility to poverty or those without a family not only restricts the number of persons with disabilities who can access support services but also weakens the possibilities of creating a robust support services system in the country. As a result persons with disabilities who are not eligible not only do not get any government aid for support services but also are unable to get services through self-payment. In such a situation the right of persons with disabilities to have access to support services is denied.

Therefore, it is suggested that India may consider means testing as a way of deciding eligibility to receive government aid for support services, similar to the system in South Korea. In this way, the legislation recognises not only the right of all persons with disabilities, which is in line with the UN CRPD, but such a process can also create a large demand for support services that are required to boost service providers and create a market of support services where persons with disability not eligible for government aid can at least pay and get good quality support services.

Equally important is how the legislation describes support providers and caregivers. Presently, it is the family who is seen as being responsible for providing care and support to the disabled family member. Such provisions in the law reinforce the existing social norms towards disability and prevent the idea of formal support services from thriving in the community. Therefore, the legislation must not restrict care and support as a family responsibility but recognise that persons other than the family can provide care and support to disabled persons.

A change in the legislative framework would warrant the involvement of different actors to ensure a smooth and adequate supply of formal support services that address the variety of support persons with disabilities require. There are three main directions recommended with a role for different actors to achieve these directions.

1. Aligning the legislation, policies and schemes with the UN CRPD

According to the UN CRPD, the government has the primary responsibility of ensuring access to a range of support services that allow persons with disabilities to live. To enable this the first step they need to undertake is bringing legislative provisions in the directions suggested above, in consultation with persons with disabilities and their organisations and other actors engaged in service provision. With a formal support services system in place,

they would be required to set standards for support services, regulate and monitor the services.

Since bringing such change in a large country like India is not easy, it may be important to maximise the resources available by becoming disability-inclusive. For instance, while the primary legislation needs amendments, equally the existing schemes and programmes must be more disability-inclusive. In this regards, schemes like the National Rural Employment Guarantee Act, 2005 may be reviewed to see whether it is possible to include formal support providers, such as personal assistants, as one of the employment options under the scheme. The scheme for assistive devices (ADIP) may ensure that the assistive and mobility devices provided to persons with disabilities support them to undertake daily living activities independently and enable them to use mobility devices inside their homes as well. The rural housing schemes run by the government to ensure homes built under the scheme are universally designed, and the scheme budget allocates funds towards adapting the house to individual requirement.

2. Raising awareness and training

In this frame, several actions are recommended for the government. First, increasing community sensitivity and awareness towards disability and disability support. For this, organisations of persons with disabilities already working in the grassroots may take a leading role. Existing community-based programs are already involved in awareness-raising. However, efforts by these programs may be in the frame of independent living for which adequate and appropriate support is a pre-requisite.

Training of rehabilitation professionals in a rights-based perspective is equally important. There is a need for rehabilitation and habilitation service providers to have the

training and develop skills to evaluate environmental accessibility of homes, workspaces and neighbourhoods of persons with disabilities to enable them to have better mobility and functioning. Awareness-raising is as much required of community members as it is for the disabled persons and their families. Therefore, besides awareness-raising of the rights of persons with disabilities, content relating to the role of support services and enabling environments may be included in school curriculums and the curriculums of all professional training.

An existing challenge, however, is that rehabilitation services are available only till the district level, thus there is a big gap in the existing rehabilitation services. Since community-based programs are few in the country, to have an all country effect there is a need for the government to strengthen these community-based programs by increasing their geographical reach to be uniformly available across the country. One key action that may be taken to enable this is by expanding the rehabilitation services that presently are restricted to the district level to the village level.

3. Involving private businesses

Considering that India is a large and a high population country, the support services to fulfil the demand may not be adequate if only offered by the public sector. Therefore, engaging with the private sector to ensure the availability of support services in all parts of the country may be required. To enable this the government needs to encourage the private sector to create support services options by increasing the demand that makes it attractive for the private businesses to invest and by supporting the development of formal support services by having enabling policies.

Private businesses can benefit from capitalising on the demand for support services by creating market support services options that persons with disabilities can use. Persons with

disabilities may pay for these services either from government aid or self-fund. To do this the private businesses may work in collaboration with the government, rehabilitation institutes and organisations of persons with disabilities. For instance, consultation with the organisations of persons with disabilities can help them provide businesses developing support services to understand and respond to the range of support services required by different persons with disabilities. Such organisations can also support them in training the workforce who would provide this support.

Finally, the private businesses can play a leading role in collaboration with other actors to undertake a bottom of the pyramid approach in the innovation of independent living and mobility devices that are culturally and environmentally appropriate for use by persons with disabilities living in rural India.