

Rearticulating Care
Disability and Palliative Care in
Low Middle Income Countries (LMICs)

*In the year 2020, the world finds itself in the midst of a humanitarian crisis. It becomes imperative, almost compulsory for care givers to revisit and redefine the idea of care so as to extend and expand it. We at Pallium India ask: **What does palliative care mean and can mean for children and adults with disability in a LMIC like India?***

What biases and assumptions are we dealing with?

The value of the role of people with disabilities in our society is undermined by:

- measuring that value in terms of contribution to economic production without acknowledging the severe accessibility issues, whether of employment opportunities or access to places of education, public toilets or drinking water.
- attempting to raise the status of a person with disability to that of a divine being with terms like *divyaang*. Such an attempt fails to acknowledge the person with disability as a human being like anyone else who has basic needs of food, shelter and employment and with fears, desires and aspirations, as one who needs to communicate with the world and with people around them. This is particularly important in the case of a child who needs opportunities to develop, learn and play.
- seeing a person with physical disability as one endowed with some sort of moral defect, or a mental health issue being related to “bad karma.”
- attributing extra-sensory and superhuman perception or computational skill to people with disability as sometimes portrayed in popular movies.

People with disabilities in LMICs like India are often invisible.

As in any other humanitarian crisis, the COVID-19 pandemic generates “an increased number of people who experience disability owing to new injuries including birth injuries, lack of quality medical care, or the collapse of essential services.”¹ Also, during this crisis like in any other, we have forgotten our people with disability (who always experience the issue of severe and chronic inaccessibility anyway) “in the contingency planning, assessment, design, and delivery of humanitarian relief”² as various measures like lockdown were enforced

For people with disability, every day with lack of accessibility is a day of humanitarian crisis.

¹ Handicap International, *Disability in humanitarian contexts: Views from affected people and field organisations* (Lyon: Handicap International Federation, 2015), 5.

² *ibid.*

Any humanitarian crisis increases suffering, pain, poverty, isolation and rejection for people with disability.

The way forward

Ensuring the right to health for everyone is the only way forward. This right entails access to proper, affordable, necessary care including free medical consultations and hospital care, long-term rehabilitation, counselling, peer support groups, door-step services of both subsidized food and medicine, accessible information (use of braille and sign language), mobile facilities, assistive technology and documents friendly to reading applications, paid leave to caregivers, and local support groups.

Accessibility is mobility, reachability and usability. Accessibility for a Person with Disability of any age is an alleviation of their suffering.

Health cannot stand independent of a person's social, economic, psychological and spiritual needs, status, and pain. For a person with disability, all aspects are frequently challenged by lack of accessibility and by inequity in economic opportunities. People with different disabilities will have different medical needs, from medications to long-term rehabilitation program, from therapy to frequent hospital visits and from counselling to palliative and end of life care.

In an LMIC like India where lack of accessibility for people with disabilities is widespread, every individual with a disability is vulnerable to serious health-related suffering. Hence, people with disability have to be de facto beneficiaries of palliative care, an essential component of their right to health.

As a voice from an LMIC, we make a plea to global civil society, governments and non-government organizations to improve accessibility and to include disability in the domain of palliative care so as to reduce the physical, social, economic, psychological and spiritual pain and suffering of people with disability.

Accessibility and health are every individual's basic rights. Because of the invisible nature of their health issue, people with disability are denied accessibility, care and opportunities. They experience serious health-related suffering and hence need to be considered de facto beneficiaries of palliative care.