

# Disability is Not a Disease – Inclusivity is a Spoke in the Wheel of Harmony and Justice

*Karma Sonam Dorji*

## Hope for a Just and Harmonious Future

Gross National Happiness, as a “measure of development process”, is for us a noble assurance and a hope for a just and harmonious society. Yet not everyone’s pursuit of “happiness” is a single unequivocal path. The common yardstick for happiness is: love and cohesion among family, community and society; material happiness; health and well-being; mental stability and a successful career. However, for some, the pursuit of “happiness” has been trimmed down to merely surviving and fulfilling their basic needs each day.

As a parent advocate for a child with special needs, to live in a just and harmonious society would mean ensuring that all individuals, regardless of their abilities, have equal access to opportunities, resources and support systems. We should prioritise equity, understanding, and empathy, ensuring that families and individuals with special needs feel valued, respected, and supported in all aspects of life – from education and health care to social and community participation.

We should understand and accept that people are different - they learn, think and see the world differently and have their own identity. We can learn to accept these differences and embrace diversity, to enrich societal cohesion, optimism and productivity.

Change is inevitable, and is required, but so are perceptions and adaptation to these changes. The rigid resistance to change and the inability to adapt, and then to continue to face these dynamic changes with the same systemic inadequacies can be costly. This burden may become more serious in the future unless we step up efforts to take action, rather than just having plans on paper. However, it is heartening to see that the focus has been shifting over the years and efforts are on the rise for inclusive schemes for people with special needs. We hope for resolute and speedy changes.

## **Agents of Change and Perception on Disabilities**

Embracing diversity can begin by amending the policymakers' and educators' erroneous perception of "disabilities" as a "problem". They try hard to "fix the problem or the child or person", in order that they "fit into society" rather than accepting disabilities as a condition and a part of an individual identity and working towards inclusive and equitable support systems and services.

The general perception of "disabilities" is of just visible ones (physical appearance, wheelchair users, persons who are blind). People with "invisible disabilities" (learning disabilities, autism, Attention Deficit Hyperactivity Disorder (ADHA), etc.) often go unnoticed, are excluded, and labelled as "rude" and "misbehaving" individuals, missing out on productive social engagements. They are unconsciously denied support systems and services.

As invisible members of society, they are seen as a burden, segregated from participation, usually not because of total discrimination (though some forms of discrimination and stigma exist) but for lack of adaptive services and infrastructure, coupled with insensitivity due to inadequate awareness and advocacy.

Those facing challenges of discrimination and stigma, particularly those with both disabilities and mental health problems, are often at particular risk of hopelessness.

Governments and public institutions have, over the years, initiated and introduced many policy reforms for providing services to children and persons with disabilities (PWDs). They have, in various measures, involved the families and PWDs in discussions to bring the real issues onto the table to recognise needs and essential service delivery. However, there is still a lot more to be done.

There is also a tendency for policies and delivery of support to shift with a change in who holds the reins of power. So far, the only perceptible constant has been the support and services provided by the CSOs in assorted limited capacities. The creation of a mechanism for consistency and commitment from the authorities will be transformative.

The drive and commitment over the years are increasing and seem positive, but a real coordinated approach with a clear leading nodal agency, and authentic involvement of the affected groups to push the cause is yet to materialise fully.

## **The Game of Numbers**

For decades, inclusivity has been just a politically correct statement, and discussions and debates were an obligation rather than a matter requiring serious solutions. The numbers did not force the attention needed because no proper surveys were conducted. As the national surveys showed alarmingly increasing numbers of people needing help, the necessity for consideration and engaging in serious deliberation has rightly increased.

For all the discussions, talks, forums, and political debates on inclusion, no matter how serious, there are those who cannot wait. Discussions should translate into real and timely concrete actions and changes on the ground. The numbers are significant and constantly increasing due to exposure to altering stressful environments, lifestyle, and other reasons that need study.

In 2017, there were 15,556 people, which is 2.1 percent of the population, living with some form of disability in Bhutan, with higher prevalence in rural and more remote areas. The National Health Survey 2023 found that the total number of self-reported disability now is 6.8 percent, comprising 48,325 people in Bhutan, excluding children under five.

The rate of increase in five years from 2.1 percent to 6.8 percent is alarming. The survey has only recorded self-reported disability and so the real number is definitely higher, a worrying data for a small country like Bhutan. Complacency is not an option anymore.

## **Shifting Burden**

With more attrition in the workforce and the exodus of the active working-age population, compounded by the rising number of the silver age group, individuals with disabilities, and families forced to give up jobs to look after children and persons with disabilities, the socio-economic burden to the nation is growing. This is a burden that we cannot brush aside, more so

now as we have graduated from LDC (Least Developed Country) status, and donors and external support wane.

The best way out is to put in place the infrastructure and mechanisms to convert the seeming burden into productive contributors of society. Equip persons with disabilities with applicable independence skills without boundaries (presently in the country, the skilling for PWDs is mostly limited to tailoring, crafts, and baking). With matching infrastructure, services and support, they can, according to their own abilities, sustain themselves and meaningfully contribute to society.

### **Burden of Parenting**

Parents of children with disabilities face difficulties with lack of professional diagnoses, equitable quality education, alternative pathways for education and learning, transitions for older children with disabilities, employment opportunities, social security, and protection schemes.

There is no equal access to ECCDs and schools for children with disabilities. The situation is far from what the policies and rights dictate because the institutions lack the infrastructure and capacity to handle children with varying forms of disabilities.

The stress related to constantly relocating and changing schools and institutions leads to frustration for parents, who eventually give up and keep children at home. They thus lose the best years of development and learning capacity.

Studies have shown that emotional and physical toll on parents and primary caregivers can lead to underlying medical conditions, such as hypertension, anxiety, and depression. They become vulnerable to mental disorders and even suicidal thoughts. Some face marital problems leading to divorce.

There is substantial evidence that parents of school-age and older children with developmental disabilities experience elevated levels of stress and depressive symptoms, above that of parents of typically developing children.

Insensitivity in communication, language, and labelling are also stressful for parents but the bigger offence is in assuming that children with disabilities

are not capable and that it is a waste of time and resources to invest in them. This prevents many parents from readily accepting and availing themselves of some services that are in place.

The health and well-being of parents are important for children. Maternal depression can have a long-lasting adverse impact on a child's brain development. Parents and caregivers have a challenging time in bringing up children in today's complicated world. Anxiety and depression are the two most reported mental health disorders in Bhutan, particularly for women aged 25 to 49 years.

Apart from emotional, mental, and physical challenges, parents of children with disabilities face financial challenges of meeting additional costs and overcoming the barriers to finding and maintaining jobs. Some of them give up working to become caregivers. It is estimated that parents spend double or three times as much in raising children with disabilities than any other neurotypical children.

The extra cost includes home adaptations, TLMs (teaching learning materials) for home, Assistive Technologies (AT), childcare, SEN (Special Educational Needs) aides, food, household bills, special transport, medical bills, therapies, etc. The support systems, therefore, should not be limited to children and persons with disabilities, but include the parents and primary caregivers, to be potentially complete active contributors.

### **Insight into Inclusion**

Families also need to understand that “inclusion”, “equity”, and “non-discrimination” begin at home. Parents of PWDs' biggest struggle is with “acceptance”. The misguided and obsessive pursuit to find a cure creates the biggest barrier in addressing the child's issues and getting timely support. How parents look at and treat their child/person consequently affects how society looks at the child/person cumulatively and collectively.

It does not help if the government and public machinery do not invest enough to understand and recognise inclusion in its entirety, let alone communicate and generate appropriate awareness and advocacy on inclusion to all stakeholders.

Inclusion goes beyond accessibility in infrastructure and accessibility to equitable and quality education in schools. It includes alternative forms and pathways of education (open learning systems and home-based education, for example), development of a learning society, and independence through meaningful productive engagement and employment.

It is encouraging to observe that the Ministry of Education and Skills Development (MoESD) has taken the initiative to make all ECCDs and schools inclusive, along with building the capacities of the teachers and facilitators. But there is also a need to look into providing alternative and optional pathways for education for many children, youths, or adults with disabilities who have not been able to access formal education.

Out of 11,347 persons with disabilities, 4,111 are literate. The total number of persons with disabilities who never attended school within the age group of three to 24 years under different domains (seeing, hearing, mobility, cognition, self-care and communication) was 72,191. This number could increase over the years.

Out of the 14,828 working-age population of persons with disabilities, only 7,254 are employed, and 7,532 (about 51%) are out of the labour force. The loss of a huge productive potential cannot be reclaimed and the increase in burden on society ignored for good.

Putting in place inclusive social protection systems is urgently needed to lessen the burdens on the affected, and give a decisive pathway for institutions to devise means to alleviate the impact of the long-ignored concerns.

## **Reflection**

An ideal harmonious and just society for people living with disabilities, and their parents, maybe where a person with disability(ties) need not even think about the disability, and where everyone will not see disability as any different from the colour of one's hair.