

From the Mother of a Child with Disability

Prashanti Pradhan

When our son was five years old, we took him to a public function at the clock tower in Thimphu, where we happened to meet an acquaintance with her little daughter. This girl looked at our son in a stroller wheelchair and innocently asked her mother, “What happened to him?” The mother flashed a very awkward look, pulled her child aside, shushed her, and pushed her away in the other direction to play.

I did not give much thought to it at the time but, later on, the scene played out in my mind repeatedly and I realised that the little girl was being taught (although inadvertently) that it was not okay to ask questions about “them”. I worried that this innocent girl would grow up into an adult who considered people who were different as “them” and also be infected by the “ableism” mindset, being in favour of able-bodied people. Just as racism differentiates and judges racial differences and considers some races superior to others, “ableism” differentiates and judges a person’s ability to function in a neurotypical manner, categorising non-disabled persons as being superior to persons with disabilities. It may be noted here that neurotypical is politically and universally accepted for the non-disabled, “normal” is considered offensive when used in this context.

The advent of modern health care in the early 1960’s has enabled Bhutan to achieve remarkable health development. The 2017 Census reveals that Bhutan’s overall life expectancy is 70.2 years, an increase from 66.3 years in 2005; infant mortality rates dropped from 40 per 1000 in 2005 to 15.1 per 1000 live births.

With the progress made in medical science, and our medical facilities having improved, diagnoses and detection have drastically reduced child mortality. This is a positive aspect of development and means that newborns who have very high chances of developing disabilities are successfully saved in the Neonatal Intensive Care Unit (NICU), despite many birth complications.

According to the Population and Housing Census, 2017, the disability prevalence rate for Bhutan is 2.1 percent, which corresponds to 15,567 persons. Out of this number, 8,111 are female and 7,456 are male. By area of residence, 3,055 persons are in urban areas and 12,512 are in rural areas. To measure disability in Bhutan, the Bhutan Living Standards Survey Report 2017 adopted Washington Group's questions on disability which covered six functional domains or basic actions: seeing; hearing; mobility; cognition; self-care; and communication. The data shows that hearing disability is the highest in Bhutan, followed by visual disabilities, and acquired disabilities are noted to be more than congenital ones.

It is worrying that many of the disabilities reported these days fall under the NDD (Neuro Developmental Disorder) category. NDDs are complicated conditions with complex and often invisible disabilities. Children with disabilities will grow up as adults with disabilities; how do we handle them? Do we set them aside because they do not fit into the mould of "normal" as defined by a society obsessed with "ableism" or do we make adjustments and accept them as one of us? What is normal but a very subjective adjective?

Unlike single obvious disabilities like visual impairment or speech and hearing impairment, Neuro Developmental Disorders are complex conditions that affect how the brain develops and functions, and are usually a combination of different conditions. They can range from mild impairments, where the person can lead a fairly normal life, to severe disorders that require lifelong care and support. Some examples of NDDs are Autism Spectrum Disorder (ASD), Cerebral Palsy, Down Syndrome, Schizophrenia, etc. Conditions like ASD and Schizophrenia are invisible disabilities and encompass a wide range of conditions, like attention deficit and hyperactive disorders, difficulty in social interaction, hallucinations, communication disorders, etc., which can also be combined with speech and hearing impairment or visual impairments. These conditions can either increase or decrease in intensity as life progresses, depending on the interventions and support provided.

Although there has been no specific data collected on NDDs in Bhutan, there is a worrying trend. All the 100 members registered with Phensem are NDDs, of which most children fall under Autism Spectrum Disorder, at 46 percent. The youngest child registered in Phensem is a two-year-

old girl diagnosed with ASD, and the oldest is a 28-year-old man with Cerebral Palsy.

Eleven years ago, in 2010, when our son was discharged from the hospital after a three-week stay at the NICU, no one advised us on what signs to look out for. Things are different now. The Ministry of Health, in collaboration with UNICEF, has adopted a universal screening tool with which Health officials across the country will hopefully be able to carry out periodic screening of children up to the age of five years and disabilities can be detected, especially “invisible” ones like autism and schizophrenia.

Elon Musk recently revealed that he has Asperger’s syndrome, Albert Einstein was believed to be autistic and Stephen Hawking lived with and died of Amyotrophic Lateral Sclerosis (ALS), a degenerating neuro condition that causes paralysis and loss of speech. These icons of society turned out the way they are because they were not labelled with a disability as young children and written off by society. Instead, they received support in various forms to bring out the best in them so that they found their strengths, and their gifts were nurtured. Today, everyone idolises them and their disability is an afterthought.

Many youths in Bhutan today are labelled either as parasites living off their parents and relatives, or losers defiling the environment with their bad habits, like gang fights and substance abuse. Many of the brilliant, the obviously gifted, the determined and some lucky ones either choose to go overseas or make use of opportunities back home to lead fruitful and productive lives. Some are left behind, struggling to find a purpose in life. Hidden within this population are those with disabilities, literally hidden because while most of them did not get access to education, the few who were could not complete it.

Programmes currently designed for youths with disabilities often come from the impression that this section of the population simply cannot manage anything beyond vocational courses like tailoring and baking, thus leaving out those with physical and motor challenges. A person living with a condition like Cerebral Palsy (CP) or Spinal Muscular Atrophy (SMA) lives with moderate to severe motor challenges, is often wheelchair-bound, does not possess fine, and in some cases even gross motor skills. They could have additional challenges like vision impairment and/or speech

and hearing impairment. However, their minds work fine, and thanks to modern innovations, they can receive education with assistive technology, adaptations, and modifications and could eventually lead productive lives.

A majority of persons with disabilities, especially adults and young adults, have not received the very basic education that goes beyond alphabets and numbers, the most important aspect of education, that is learning to co-exist in society. For now, persons with disabilities are seen by the Bhutanese populace as objects of sympathy, objects that need help and objects that may be an opportunity for someone to fulfil one's karmic debt. Persons with disabilities are not perceived as equals, as fellow human beings, as persons who have promise and potential to occupy a productive space in society. This is evident from the fact that schools and Early Child Care and Development (ECCD) Centres do not accept children with severe disabilities because they believe these children cannot learn and infrastructures are not accessible. Many a time parents themselves say that a child with a disability was born into their family because of some karmic debt.

Our Constitution states that education is the basic right of every Bhutanese child and parents see education as empowering and a social equaliser. However, accessing education has been the biggest challenge for parents of children with disabilities, not just physically but financially too.

For example, 12-year-old Ngawang has a brilliant mind and scores the highest marks in his class. He was not accepted in the first school his parents took him to because he cannot move without the help of a wheelchair and the school management immediately assumed that his mind was as disabled as his body. He says his ambition is to be a scientist, or Bhutan's first Prime Minister in a wheelchair.

Twenty-one-year old Khushi is non-verbal, cannot move without support, and is completely dependent on someone for her care. She went to school until Class II, after which her parents could not afford the extra cost of hiring a taxi every day and giving up the income of one parent, who would have to stay behind in school with Khushi to give her the extra support she needed. Today Khushi stays at home, communicates with the help of a mobile phone, enjoys watching drama on TV and is a joy to her family members, but she requires constant help and is a liability.

Eleven-year-old Siddharth is a foodie and loves travelling just to eat. He enjoys music and has a wicked sense of humour. He is wheelchair-bound, with visual impairment, and is completely dependent on someone to take care of him. He cannot adopt the traditional way of reading and writing, but learns through hearing, and is learning to use the accessibility features of a computer. While Siddharth has not yet developed cognitively to the extent that he understands the concept of future and ambition, his parents look at what he enjoys and dream of Siddharth running his own karaoke restaurant or earning a living as a blogger when he grows up.

These are a few of the hundreds of hidden stories in our country. Some children never got the opportunities that would have helped them, and others hope that they will not be left behind, and dare to dream. Not every person with a disability will end up as someone like Elon Musk or Stephen Hawking, but does that mean that they do not deserve an opportunity that could possibly ensure that they are productive members of society instead of a liability?

Bhutan is one of the few remaining countries yet to ratify the United Nations Convention for the Rights of Persons with Disabilities (UNCRPD). The government, however, endorsed a National Policy for Persons with Disabilities in 2019. The Ministry of Education has drafted guidelines and standards for inclusive education, and there are various Civil Society Organisations (CSOs) established to work for the upliftment and inclusion of marginalised sections of the population, like Disabled Persons Organisation (DPO), Draksho, Ability Bhutan Society, Tarayana Foundation, RENEW, etc, which work with persons living with disabilities, directly or indirectly.

One of the obstacles to creating an inclusive society is lack of awareness; people fear the invisible and the unknown, and parents and families of children with disabilities play a big role in acceptance at home, followed by advocacy in society.

Parents and families of children with disabilities came together informally in 2017, and as a registered, legal entity in 2020, to form Bhutan's first parent support group, Phensem Bhutan, to empower parents and caregivers to try and create an inclusive Bhutanese society. While there are many experts who have trained in the field of disability, parents have lived the life, and

it is Phensem's belief that they will be able to identify the real gaps in the system so that the government can work towards providing the necessary support to address them.

For now, parents believe that the first step towards introducing the society to disability is to make education accessible to all children with disabilities, irrespective of the severity of their condition. While the government has been working towards providing guidelines to schools to adapt and modify curricula, children with severe disabilities who need extra support have not been enrolled in educational institutes.

Children with all kinds of disabilities can learn if they have extra support in the form of aides, use of assistive technology, and an accessible environment. The State must also look at alternative forms of education, like functional education which, as opposed to the presently followed curriculum-driven education, focuses on real-life skills, identifying a child's strengths and building up on them to eventually lead to independence. This includes home-schooling or open schools, where children who cannot follow the regimented structure of mainstream schools can learn in an alternative environment at their own pace, with different levels of assessment to suit the capabilities of different types of abilities.

To quote Albert Einstein: "Everybody is a genius. But if you judge a fish by its ability to climb a tree it will live its whole life believing that it is stupid."

Phensem dreams of an inclusive Bhutan where every ECCD centre and school readily accepts any child irrespective of their abilities; and children with disabilities can attend a school closest and most convenient to them, like their typically developing peers, instead of having to travel to a designated Special Educational Needs (SEN) school not necessarily in their neighbourhood.

To make a school compound accessible, children with physical challenges can be assigned to classrooms on the ground floor, where the school need not install elevators or long ramps. Instead schools can provide a short ramp to access the ground floor, and ensure that clear, even pathways are safe for all children -- disability or no disability.

Teachers do not need to undergo a Masters degree in Special Education to be able to impart knowledge to children with special educational needs. A certificate course is enough to get them started; most of the learning happens on the job. There are numerous methods, ideas, and tactics to adapt in school, in public spaces, in life, to accommodate disabilities (that would be a whole book, maybe even more). The first step is to be aware of the person as an individual and set aside any doubts and misgivings; a fellow citizen who may be different from you deserves the same amount of respect as you.

Parents and families of children living with disabilities have their role to play in the form of building their children's confidence and reducing the fear that they will be labelled, ostracised, or stigmatised. It has been proven that children with disabilities thrive when placed with typically developing children in an inclusive classroom, and the children learn to adapt, co-exist and accept children with disabilities as a part of society. They learn that it is okay to be different.

Acceptance is the key word here. It is possible to accept persons living with disabilities into any space without doubts, fear, or misgivings. They are as much a part of society as any able-bodied or able-minded person. It is also worth keeping in mind that all of us are only temporarily abled. If you suffer from a stroke or an accident tomorrow, you will also need that acceptance and that ramp.

The sick, the elderly, and the disabled aspire to visit places of worship like monasteries as much as abled-bodied persons. Everyone, irrespective of their physical capabilities, enjoy public spaces and all children want to play wherever they can. Physical accessibility in our country is not easy, considering our difficult terrain and topography; sometimes it is difficult even for able-bodied persons to navigate dangerous steps and certain footpaths. However, if ramps are constructed wherever possible, (properly designed safe ramps instead of a steep afterthought placed carelessly by the corner of some stair) it may not be necessary to spend extra on stairs and a badly made ramp. Inclusion is not about segregating a certain population into a separate facility, no matter how sophisticated that facility may be; it is about learning to accept each other, include each other, and co-exist in harmony.