

Life without Limits

THE WORLD OF THE **DIFFERENTLY-ABLED**







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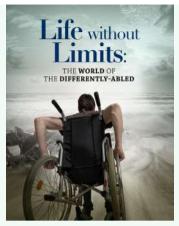
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Cover: Life without Limits

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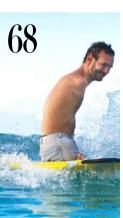












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Life without Limits

This issue of Pax Lumina focuses on the world of the differently-abled. When this topic was mentioned, there were some eye-brows raised, politically correct ones for sure. The world of the differently-abled, according to those eyebrows, conjures up an image of a different, separate world for some of us who are less fortunate than those "abled" inhabiting the rest of the society. We agree; but also disagree. Yes, discrimination of all forms reinforces stereotypes which perpetuate further discrimination, exploitation and cruelty. But, on the other hand, if we do not talk straight and hide behind politically correct and diplomatically acceptable gibberish, truth will hidden from those who can face the truth and act for change. This magazine addresses such people.

When we looked at what we thought to be the world of the differently-abled certain things became clear. There is no clear boundary between the world of the differently-abled and the world of the so-called abled. It is all mixed-up and fuzzy. There is only one world of people, all differently-abled in different ways. Of course, there are those who care and those who have yet to learn to care. While the former does their best to share their abilities with those who need them, the latter just talks and talks. But all of us, I am sure, will agree that one of the biggest problems facing the world today is pollution. It is noise pollution. Instead, we need action. And we feature some of those who have reached out to their neighbours on this planet with hope, dream and empathy.

It is also true that the differently-abled do not form an undifferentiated mass of humans waiting for our sympathy. They too have a right to live a life of fulfilment and honour here.

Many people do not even understand what autism is. The interview of our Managing Editor with Sugandha Sukrutaraj will open their minds. That autistic children can be enabled to become computer experts will defy their wildest imagination. But as you will see Sugandha has done it. There are many other stories of those who have transcended their limits and sought empowerment of others and themselves. We have featured some of them.

One major hurdle existing in India along with some other countries for the physically challenged is access to public spaces. I remember that when the great cosmologist Stephen Hawking came to India years back in 2001, he had sharply commented on this inaccessibility to our great monuments. Imagine this was from a man who could penetrate the secrets of the universe! There have been changes, but mostly at the legislative front. Here too action is what is needed. In this connection, let me also refer to the article on Architecture and Peace by Leanne Dmello.

It is hoped that our readers will find material for thought in this issue of Pax Lumina, as well as inspiration for action.

Pax Lumina extends Christmas and New Year greetings to all of our readers.

Jacob Thomas Editor

Editorial

National

A bend in the road is not the end of the road. Unless you fail to make the turn.

- Helen Keller



Sugandha Sukrutaraj / Binoy Jacob

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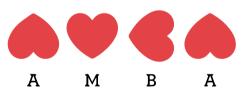
Integrating the Intellectually Challenged into the Mainstream

Sugandha Sukrutaraj founded AMBA, a registered Trust, in 2004 and AMBA Certified Partner Centres (ACPCs) to enable Economic Empowerment of the Intellectually Challenged. Through these ACPCs, she integrates young people with cognitive disabilities into the mainstream by training them for back end information technology jobs using the computer functionally. This eradicated the stigma, while empowering them economically, giving them a sense of purpose, making them contributors to their home and society at Large. Using an in-situ authored benchmarked curriculum, AMBA trains these individuals to perform data entry work that is outsourced to AMBA.

This is a community of independent, able and empowered 'computer operators,' changing the way we think of those challenged intellectually.

Sugandha speaks to Pax Lumina.

The children turned out to be contributors and this brought in a paradigmatic shift in the perception of parents towards their children. This improved the self-esteem of the youth who are often neglected, even in their own families. Since then, parents never talked about the disability of their children. This is the reason behind my setting up AMBA.



Could you share with us the inspiration behind the starting of AMBA?

I grew up in a military family and got married at the age of seventeen. My husband was a Fighter Pilot and military attaché to Thailand representing the Indian Armed Forces. But, he died in 1990 due to cancer. Thereafter, I educated myself and three years down the line, I developed into an aviation marketing strategist. I had two boys of 14 and 16 years of age. The most important priority at that time was to rehabilitate my children and I.

As a strategist, the first assignment I got was organising the first Air Show in India - Avia India '93, managing a team in

Bangalore, coordinating and networking with the Indian Air Force, the Karnataka and Central Government, and marketing participants from 21 countries. This was very successful and was taken over by the Defence in 1996 and christened Aero India. I worked for ten years in the industry and felt saturated after the Air Show. Meanwhile, I had exposure to the visually impaired through the publication of a Braille Magazine for 354 blind schools in India. Soon after, the Ministry of Information Technology, Government of Karnataka, invited me to do research on the possibility of showcasing technology in a computer-driven atmosphere. Showcasing and equipping experiences to include the disabled community really interested me and made the experience truly inclusive. For almost two-and-a-half years, I did extensive research. For this, I got the support of the Central Government also. I travelled widely at my own cost to make comparative studies and came up with a comprehensive report. Unfortunately, this project turned out to be a failure due to political reasons.



The children who had not seen or touched a computer acquired the skill in a short period because they had nothing to unlearn. When the educators asked the beneficiary operators questions, they could answer them by operating the computer functionally and not orally.

In 2000, Air Marshal Denzil Keeler invited me onto the National Board of Special Olympics in India, which introduced me to the community I serve today. Before this, I had no idea of this community with very low IQ. The reasons for the disabilities are often early marriage, malnutrition, brain injury, domestic violence during pregnancy and lack of medical service. Later, I learned that 30% of this community had no place in society.

I worked with 26 Indian States. We imparted training to enable them to participate in the Special Olympics held in Ireland in 2003. About 81 children, aged between 15-18, secured 110 medals. All, including their families, felt dignified when they were honoured by the government offering prizes in cash and kind. But, when we approached various Ministries for securing employment, the response was not positive.

Many wondered how could people with disabilities be provided with employment? But the then Minister of Petroleum, Mani Shankar Aiyer, offered Rupees one hundred lakhs as a reward for their great achievement in an international scenario competing against 155 countries.

The children turned out to be contributors and this brought in a paradigmatic shift in the perception of parents towards their children. This improved the self-esteem of the youth who are often neglected, even in their own families. Since then, parents never talked about the disability of their children. This is the reason behind my setting up AMBA. Though I had no experience in this field, I was highly motivated to take it up. What I lacked was the experience, but I had the will.

Another inspiration was the life and work of Fr Francis Kureeckal, the Director of Asha Bhavan, with whom I had the good fortune to work closely for three years in various schemes for the empowerment of women. We were able to provide water in almost 29 villages. The women were given training in candle making and other income-generating projects. To enable sustained employment Fr Francis helped to set up Self Help Groups to enable dairy farming. In all, 400 women were given training. I realized the amazing potential of computers for empowerment and distanced myself from Special Olympics and started AMBA. I wanted to implement this idea for the benefit of the differently-abled. I was able to enlist the support of the Air Force, Training Command in Bangalore, Air Marshal Pandey, the Chief of Training Command, provided me with the trainers and the infrastructure facilities including three self-contained rooms.

In my interaction with the intellectually disabled children and their parents, I understood that though they had a low IQ and were lacking in social skills, they were gifted with multiple talents around visual matching processes. Using the computer functionally was their forte. In 2007, I went to Jeevodaya, Nagpur and gave training to 20 adults. In Ujjain, Madya Pradesh there was a girl, called Megi, with musculardistrophy, who I remember, was able to type with her feet.

Over and above, India is home to over two million cognitively disabled people, out of a total disabled population of nearly twentytwo million. Intellectual disabilities are poorly understood in India. It is commonly thought, even among educators, that anyone with an IQ of less than 65 cannot participate in mainstream activities, least of all join the workforce. This limits the economic opportunities available to the cognitively challenged, leaving them marginalised and disempowered.

What is the type of training in AMBA?

 My experience in Nagpur helped me evolve the AMBA Curriculum.

After two days of unsuccessful search for work, we came back to Jeevodaya feeling dejected and there we met the auditor. Conversation with him led us to meet the Managing Director of Dinshaw Ice Cream who immediately pointed out to a large volume of back office data entry work available documenting receipts of the inflow of farmers and SHG women to the Dinshaw Ice Cream milk collection centres. When I saw the work it was being done in 3 languages, disappointing as our youngsters could not type in the vernacular as reasoning was involved. But, when I looked again I realised that they were not typing, instead selecting from drop down options. For example, cow/buffalo; morning/evening which was a different image in any language. This is how I evolved the curriculum.

We first use the computer to reinforce the alphabet as an image using Google images within a different topic every day. We concentrate on one alphabet from these images, take them through different experiences of just 15 minutes each winding up with making flash card of each alphabet. At the end of 26 days, 20 trainees have 520 flash cards which are scattered on a table. If, on that day, we are discussing colours, and GREEN is the word on the board, we use the flash cards as the keyboard select G...R...E...E..N and form the word Green visually ... which is really an experience in data entry without the computer. This constitutes a beginning and the curriculum takes them forward into functionally using the computer within existing software.

The children who had not seen or touched a computer acquired the skill in a short period because they had nothing to unlearn. When the educators asked the beneficiary operators questions, they could answer them by operating the computer functionally and not orally.

Special educators at the onset of collaboration to set up ACPCs are taught the curriculum using operators from the AMBA Core Center in Bangalore (ACC) using low functioning Tora and as the degree of difficulty increases; we use operators with higher ability to ensure the Special Educators understand the limitations they are dealing with. The criteria for education does not revolve around educational qualifications but age to avoid child labour. Those with IQ below 65 are preferred to focus on adults who have no other opportunity.

Our training is holistic and includes basic life skills, such as self-care, to improve social skills, and how to travel alone using visual matching processes.

A very important part of the training is simulated work training using mock data to maximize their efficiency as you can get work out of sympathy and empathy but to get continued opportunity one has to meet the service level agreements of the company like accuracy and timeline. Our youngsters never fail which is why AMBA is successful. Even though, our young operators can collectively achieve only 10-20% compared to a mainstream operator.

The training enables successful data entry, mail merging, receipt printing, scanning signatures for client verification, posting and dispatching. The youngsters who have completed the training become trainers themselves. The training period lasts a minimum of six months and can take up to two years depending on the youngster's ability.

My strategy brings together government agencies, the armed forces and corporations, which, along with participants and their families, become stakeholders in training, placing, and supporting young people as they become employed.

What about the administration of AMBA?

After the loss of my husband in 1990, I married again in 1999. My husband was a Captain in the Navy and gave up his work to join hands with me at AMBA as he was fascinated with the success of the community. He took over the administration and technology as he was an armament We have already but it is not enough to teach people how to fish. We hope, with God's infinite grace, to generate a fishing industry filled with appropriate opportunities for this capable community.

technologist. From 2003 to 2015 we had a decentralised environment where all finances related to work were handled by the ACPCs directly. In 2015, we were supported by a weel-known Foundation for three years and networked and started ACPCs in the next three years with 475 organisations addressing a total of 8000 kids in 25 States in India. 80% of our work is carried out in villages and the rest 20% in small towns and a few cities. About 37% today are women.

How about AMBA's networking with companies?

In 2004, AMBA had a humble beginning with 10 persons. Intel provided us with desktops worth Rs 5 lakhs. Then I started collaborating with people of goodwill along with Intel and the Air Force. I used my military and corporate background to work with major corporates like Microsoft, Tata Teleservices, Reliance Telecom, Airtel, Idea and CMIE, to name a few.

Did you get any support from the government?

In my experience, government interventions were not sustainable.

There was some initial enthusiasm, but there was no follow-up.



Have you ever had any discouraging experiences?

We got several orders from various companies and our kids executed all of them meticulously. Unfortunately, a few companies disappeared without making payment. They may have their reasons. A few companies had entered into a subcontract.

Can the differentlyabled be integrated into mainstream society after the training?

In all, 532 operators are already doing mainstream jobs. For example, some of our kids are employed in the international airport, Bangalore. Some are engaged in schools as assistant librarians for data entry. The list goes on. About one thousand children are engaged in entering the details of the athletes of Special Olympics into the International Games Management System.

However, they are a highly vulnerable group subject to various types of abuse and exploitation. Sometimes, the relatives are the abusers. There was a 15-year-old girl in Nagpur. While her father was away at work a few men used to come and molest her. He realised it one day when he came home early from work. They told the girl she was doing a good job and for that, they used to give her gifts. The men attacked the father, but he was saved by the neighbours. Now, these people are in jail.

P How can an institution collaborate with AMBA?

• For collaborating with AMBA, the organization must be a registered one. Another requirement is that the training of trainers must be imparted at Bangalore so that the trainees can have first-hand experience with people of varied IQs and how they perform. In six days, the trainees, often with low IQs, become trainers or special educators with multiple skills in computers.

Have you received any recognition or awards?

• AMBA was the Best NGO in Karnataka (2016). We won the Helen Keller Award (2015). This is given by the National Centre for Promotion of Employment for Disabled People. Other awards included the Global Sourcing Council's Impact Sourcing Award (2015). The function was held at the United Nations headquarters at New York. We also won the NIMHANS Felicitation in 2010, and the DeRozio Award (2008) which is given for excellence in the field of education. We are also Fellow-Ashoka Innovators for the Public, (2007).



How do you envisage your future projects?

 God has been the guiding hand throughout my life, right from my association with the aviation industry through various projects such as women empowerment, Self Help Groups, and finally AMBA. I give credit to the children I have been entrusted with.

Post the Corona Virus Pandemic 475 ACPCs were closed down at the behest of the Government. AMBA strategized a solution to work from home using the internet and remote access existing software available free on the internet and has revived 63 ACPCs. In all, 756 youngsters are ready to do backend work data processing of Bombay Stock Exchange's Bhav Equity forms dating back to 1951 for analysis for the future. The first phase completed in August is presently going through audit and the second phase will ensure continued work to 756 beneficiaries. Volunteering is the urgent need at AMBA to ensure more genres of work opportunities.

We have already trained many, but it is not enough to teach people how to fish. We hope, with God's infinite grace, to generate a fishing industry filled with appropriate opportunities for this capable community. Please join us in our efforts.

Another major constraint is the lack of funds. We are looking for a partner to support our endeavors for the next five years to enable sustainability without external funds. We truly believe that we can do this. We have the will and the administrative setup. But, all our existing centres which were closed down due to the Corona Virus Pandemic must be revived.

Those who would like to support the works of AMBA please visit **www.ambaforlife.org**



Doulallem Neihsial doulallemneihsial@gmail.com

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Journey

was born on May 8, 1988, at Leikot village in Manipur. In 1994, due to a conflict between the Kuki and Naga tribes, our village was burnt down by the Nagas. We settled at Gangpimual village in Churachandpur district. In later years, we moved to different places owing to my father's pastoral work.

My Family

We are ten including our parents. I am the sixth among eight siblings. I have five sisters and two brothers. Four of my sisters and one brother are married. Now, I remain with my parents.

My Social Life

Since my childhood, I was fond of playing football and volleyball with my friends. I am one of the players on these teams. I was also active in different kinds of social activities. On the other hand, in my Christian life, I was an active member in the church. I represented the youth as a finance secretary, treasurer and general secretary in the executive committees of the church.

However, owing to financial problems in our family, I decided to join the Indian Army. I went for the interview seven times, but was rejected due to a damaged eye.

In 1992, while I was playing, one of my friends hit my right eye with his pen. I was hospitalised for one month. From that time onwards there has been a dark point in my eye. I could not see clearly. But there was no problem with my left eye.

ife has its ups and downs. No matter where we are, we face difficulties. Though life is challenging, the hope we have in God can overcome our problems.

However, after my Matriculation, I went to the forest with my uncle on August 23, 2007. Unfortunately, he misfired his gun. The bullet passed through my left eye.

I was operated on three times but my sight could not be saved. At the same time, I lost my sense of smell. But luckily, by the grace of God, I was alive. Though I lost my vision, I did not suffer any depression because my happiness remained in Christ. I decided I would preach the gospel of Jesus till my last breath.

Educational History

In 2007, I completed my matriculation from Rayburn High School. After a three-year gap due to my accident, I could hardly continue my education. Later, I stayed for five years at the Salvation Army Home for the Blind in Kolasib, Mizoram. It was while there that I did my BA in English literature from the Government Kolasib College in 2015.

On June 10, 2016, I joined the Bachelor of Divinity course at the United Theological College (UTC), Bangalore. I completed my theological studies in 2020.

The UTC is a place where my morale was boosted. I learnt many things from college. The UTC community encouraged and moulded me to be what I am today. I would like to thank the Principal and the community for their physical and moral support.



My project and objective are to build an inclusive church in our Christian community. To have a good understanding and relationship between the church and the differentlyabled, so that our churches may become disabledfriendly.

Life has its ups and downs. No matter where we are, we face difficulties. Though life is challenging, the hope we have in God can overcome our problems.

My commitment is to serve God and give my life for his glory. My priority is to reach out to the unreached with the light of the gospel and share it with my disabled friends.

Since persons with disabilities are still marginalised, many of them are in the dark. The society also is unaware of the rights and dignity of the PWDs (Persons/People with Disability).

The so-called disabled people are also human. They have the same senses that we have. The thing is that they have some difficulties or impairment in their movement or abnormalities in their body functions that have to be addressed.

Since we are all having the same spirit, mind and soul, let us treat them as what they are. No doubt, many NGOs and institutions have arisen to care for the PWDs. But, there are still many miles to go to reach the unreached.

From my personal experience, as a theologically-trained person, some of the churches open a way for the PWDs, but still, some are yet to awaken from their sleep. Even my ordination has been brushed aside because of my disability. The church must be the main source of inspiration for disabled people. But, very little encouragement is found there.

By observing the infrastructure of the church and the worship patterns, most of the churches are not disabled-friendly. This creates a sense of inferiority among the disabled.

My humble prayer to the society and the church is: let us love our neighbours who are with disabilities. Let us not be the stumbling blocks for them. Instead, we should become their pathfinder.

The disabled expect great things from normal people, so please show concern for them. And if we cannot help them, let us not disturb them.

With the grace of God, I work as the coordinator of the National Council of Churches in India- Indian Disability Ecumenical Accompaniment.

My project and objective are to build an inclusive church in our Christian community. To have a good understanding and relationship between the church and the differently-abled, so that our churches may become disabledfriendly. Where all of us may worship the Lord without any discrimination.

Author is from Manipur, India and the coordinator of the National Council of Churches in India- Indian Disability Ecumenical Accompaniment.



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An Ongoing Journey

bhishek Thakurworks as an Assistant Professor in the Department of Social Work, University of Delhi. His journey from one of the remotest areas of Madhya Pradesh to one of the prestigious universities of India has not been so easy.

The 35-year-old Abhishek, from the Seoni district in Madhya Pradesh, was born with a visual disability (retinitis pigmentosa). As he came from a remote area, the people had little understanding about such a disability. He began his education in Seoni but due to a lack of sensitivity and ignorance on the part of the school authorities, he was forced to move to Nagpur. He took admission in a special school where he studied till Class three. Later, he shifted to Delhi and got admitted to the Jormal Periwal Memorial Senior Secondary School for the Blind, which is run by the Blind Relief Association. This is one of the pioneering institutions working in the field of visual disability in India.

After his schooling, he secured admission to the prestigious St. Stephen's College, New Delhi. His transition from a special school to the college was a paradigm shift where he put extensive efforts to inculcate diverse learning through different milieus.

After his schooling, he secured admission to the prestigious St. Stephen's College, New Delhi. His transition from a special school to the college was a paradigm shift where he put extensive efforts to inculcate diverse learning through different milieus.



At St. Stephens, he got a lifetime opportunity to explore and enhance his skills in academic as well as extracurricular activities. This was a rare opportunity for people with disabilities due to the lack of understanding and social stigma. Later, he joined the Tata Institute of Social Sciences (TISS), Mumbai.

At TISS, he got the practical experience of existing social realities. After the successful completion of his Masters in Social Work, he was awarded the Gold Medal for being the best student in fieldwork. He joined SCORE Foundation as a research officer where he did the advocacy work for the Unified National Scribe Guideline for Persons with Visual Disability. This guideline was passed by the Ministry of Social Justice and Empowerment in 2013. The guideline removed various barriers which were faced by persons with disabilities while writing exams.

After leading several projects at SCORE, Abhishek went to pursue his higher education at TISS, Mumbai. Later, he got an opportunity to teach at the Department of Social Work, University of Delhi. The experience of working in the department was phenomenal due to the working atmosphere which is quite enthusiastic and based on the principle of equality. Such an environment motivated him to further groom his abilities and competencies.

He organised three mega job fairs for disabled persons. They were able to become active contributors in the job market in different capacities.

He is a member of the Expert Committee on Disability Employment set up by the Government of Delhi. He is also an expert member of the labour department. He also served as a member of the Task Force Committee, National Skill Development Corporation, Government of India. He has completed various research projects on community-based rehabilitation and sustainable livelihood framework in collaboration with CBM, an international organisation working in the field of disability. He has also published articles on employment and disability, water and health, and skill development.

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Understanding Learners with Disability

The moment we think of the initials PWDs, we tend to perceive them as children and persons who are incapable of being like 'us'. We tend to be guided by a welfare attitude rather than seeing them as empowered, independent, contributing and responsible citizens.

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he first step is to start addressing myths and perceptions that all Persons With Disabilities (PWDs) need to be cared for and handled. We also need to introspect, reflect and respond to a critical question: Are PWDs a standalone category? I believe they are not.

The New Education Policy, 2020 (NEP) endorses the Rights of Persons with Disability Act, 2016. There are 21 categories in this Act. But the moment we think of the initials PWDs, we tend to perceive them as children and persons who are incapable of being like 'us'. We tend to be guided by a welfare attitude rather than seeing them as empowered, independent, contributing and responsible citizens.

This change of attitude, perception and approach is a must. This has the potential for sustainable education as visualised under the Sustainable Development Goals 2030. India endorses this. The NEP 2020



also talks about the gifted, and respecting the Act as well as ensuring equitable access and opportunity to all. The abilities and disabilities occur for PWDs in the same manner as those that exist for any other human being.

The Supreme Court's order of October 28, 2021, has already paved the way for the Central and State Governments to be accountable. I am sharing some documented cases of the potential of PWDs so that each of us can respond to all PWDs with respect and dignity.

Evidence of PWDs with Potential

Mohammed Akhil Pasha was born in a rural village in vulnerable circumstances with developmental delays and key challenges including a delayed birth. In addition, poor awareness and poverty further deepened the vulnerability. As there was no option, he continued education in the normal school up to Class 7 and later left it due to poor education and barriers. in Telangana, identified him in 2005 as a child with mental retardation and provided him with training and rehabilitation skills. He was the leader of a self-help group and remained involved in forming several such groups which led to their social and economic development. By training in office work, he became an employee with 'Manochetna'.

His colleagues appreciated his performance as he is systematic in doing the works assigned to him. Mohammed was able to achieve economic empowerment. Following a significant change in his attitude and behaviour, he was able to marry a nondisabled girl in 2007. He is blessed with two daughters. They are normal in all aspects.

His aged parents stay with him. Mohammed is the only son and the worry of their parents about what will happen to Mohammed after they die has been minimised. He is a role model and an answer to several myths of disability. By availing of the benefit of Niramaya, he is the ambassador for taking the schemes and benefits of the National Trust to the unreached targeted groups. He is looking forward to becoming selfemployed. From extreme hyperactivity and epilepsy to a life of content and purpose. That is the story of Karan Srivastava, an adolescent with intellectual disability, autism and epilepsy. Karan suffers from the congenital disorder 'Tuberous Sclerosis. He was diagnosed at eleven months. He had patches (tubers) in his brain. This caused the constant recurrence of epileptic fits and a big white patch on his right calf.

Karan was extremely hyperactive and could not sleep for more than four hours. He could not maintain eye contact or focus attention on any object for more than a few seconds. His physical milestones were normal but his cognitive/intellectual capabilities lagged behind the normal range of development. By the age of three years, the problems seemed to pile up.

Karan's deviance from the normal range of development became pronounced. He had not developed any speech abilities and was unable to communicate effectively through non-verbal means. Karan became obsessed with a comb and a ball. His doctor put him on a very high dose of anti-epileptic medicines. This had side effects like loose motion and loss of appetite. At three-anda-half years, he started a ketogenic diet to curb epilepsy. Karan was on the diet for three years. It arrested the epilepsy by the time he was six-and-a-half years old. Karan underwent speech therapy, occupational therapy, sensory integration therapy, and handle therapy.

Karan was enrolled in a special school for autism at the age of eight years. The structured environment helped him understand this world a little better. The routine and the specially designed teaching methods helped improve his sitting tolerance. He was able to achieve toilet training and learned to do daily living skills like eating, dressing, and bathing. He also learnt need-based communication and was able to identify and label objects in his daily environment.

From the age of 14 years, Karan was trained in pre-vocational skills like cooking, cleaning, and packing. Later, he received training to make items like chocolates, paper bags, and jewellery. Each task that had to be learnt was broken down into some steps and taught one at a time. Today, he is in a vocational centre and assists in the production of many items which are sold at exhibitions.



From extreme hyperactivity and epilepsy to a life of content and purpose. That is the story of Karan Srivastava, an adolescent with intellectual disability, autism and epilepsy.

Karan loves going for a daily walk with his parents, watching TV with his younger sibling, and spending time with his family. He goes on a weekly family outing. His journey from an extremely hyperactive and difficult child to a calm person with something to do in life has been extremely rocky, but successful. His disability has not deterred him from acquiring a life of meaning and dignity.

Visually Impaired Filmmaker Anand Kulkarni

In an episode of Eyeway Conversations, Anand Kulkarni, the first and only visually impaired filmmaker in Asia, spoke about his life. At the age of seven, Anand was diagnosed with macular dystrophy which led to a gradual loss of sight. But he managed to study with assistive technology and a great deal of support from his family. When Anand applied for a Bachelors in Mass Media, Mumbai's top colleges rejected him. Eventually, he got admission to KC College. He calls his 36 failed projects in college the best lessons in life. He was enamoured by the idea of creating something out of nothing and he relied on his ability to hear everything minutely, or as he calls it, 'shameless eavesdropping'.

With over 100 digital works to his credit across fashion, luxury, music, liquor, home decor, lifestyle, healthcare and sustainability, Anand is an award-winning director.

You may tune in to listen to how a visually impaired person ended up in a visuallydriven industry of filmmaking.

https://anchor.fm/eyeway/episodes/Eyeway-Conversations-with-Visually-Impaired-Filmmaker-Anand-Kulkarni-e199gns To access the podcast transcript, click on the link:

https://otter.ai/u/ Rx8nYHboTFPJim5n53wVRy9hpN4.

Learning Difficulty and Professional Excellence

Abhishek Bachchan was diagnosed as a dyslexic in his childhood and attended a special school. In the long run, Abhishek conquered the disorder and shone as an actor. Similarly, because of dyslexia, the actor Boman Irani remained a below-average student and almost everyone at school ridiculed his lisp, making him extremely self-conscious. He believes a person should keep challenging himself.

"When I was a waiter and I started getting nice tips I got comfortable," he said. "You have to jump out of that comfort zone. Then I became a shopkeeper and a photographer. I got comfortable and jumped out of it. Always jump out of comfort because it is a dangerous thing. You work for comfort but staying in a comfort zone is very bad," said Boman.

Being Different Can Be A Gift

Greta Thunberg's parents say their daughter, once painfully introverted, was always a bit different from other children. Four years ago she was diagnosed with Asperger's Syndrome which helps explain her remorseless focus on the core issue of climate change after overcoming depression.

"Being different is a gift," she told Nick Robinson on Radio 4's Today's programme. "It makes me see things from outside the box. I don't easily fall for lies. I can see through things. If I had been like everyone else, I wouldn't have started this school strike for instance."

In India, this work has started and one significant publication appeared in 2016. The twice-exceptional is a segment of the population in whom extraordinary abilities coexist with disabilities. The National Institute of Advanced Studies, Bengaluru has been working on this issue.

Students who are gifted and talented often remain neglected in India. Since these children have exceptional abilities, they demonstrate special needs during the period of their development. Gifted children have high cognitive and emotional needs which are not met in usual classrooms geared to the average learner. The fact that these children are in the minority adds to the problem of Gifted children have high cognitive and emotional needs which are not met in usual classrooms geared to the average learner. The fact that these children are in the minority adds to the problem of alienation and a sense of loss of direction.

alienation and a sense of loss of direction. Both teachers and parents of these children struggle to fulfil their learning requirements in terms of information, resources, providing opportunities and extending emotional support to them(Kurup, Feb, 2021, p.472).

We all need mentors and mediators to help us identify our potential.

The author is the former Chairperson, RCI and Professor NIEPA.

I. Supreme Court Order on Special Educators, 28 October 2021. This link summarises the order and also gives the link to download 100 pages of order details.

https://www.livelaw.in/amp/top-stories/supremecourt-special-teachers-divyang-students-184596

II. Kurup, Anitha and Dixit, Shalini (2016) Gifted with Disabilities: The Twice Exceptional in India. Indian Educational Review, 54 (2), pp. 7-25.http://eprints.nias.res.in/1713/ accessed 31 October 2021 III. Kurup, Anitha (2021) Challenges to identify and mentor gifted children in developing countries: the Indian experience, CURRENT SCIENCE, VOL. 120, NO. 3, p.472, 10 FEBRUARY 2021/http:// eprints.nias.res.in/2059/

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Pax Lumina 2(6) / 2021 / 25-26

An Inspiring Wheelchair Missionary

The obituary of Fr. Sebastian Thengumpally



ebastian Thengumpally, SJ went to his eternal abode on October 27, 2021. Sebastian was humble, committed and a holy Jesuit. He was my guardian angel and companion in the Novitiate. I always felt that Sebastian remained a guardian angel and companion to the poor, the differently-abled, underprivileged and all those who required his support and care.

Sebastian was born on May 22, 1962, at Paippad in Kottayam, Kerala. After his pre-degree studies, Sebastian joined the Society of Jesus on June 19, 1981. He did his pre-novitiate at St. Xavier's College, Thumba, and the Novitiate at Christ Hall, Kozhikode. Following his juniorate studies at Beschi college, Dindigul, Sebastian joined St. Joseph's College, Devagiri, Kozhikode, for his degree studies. He completed his philosophy from Satya Nilayam, Chennai, and theology from the Jnana Deepa Institute Of Philosophy And Theology, Pune and Sameeksha RTC, Kalady.

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He was ordained on December 28, 1997. Sebastian did his Tertianship at the Xavier's Teachers Technical Institute, Patna, and pronounced the final vows on August 15, 2002. From 2002-2018, he was the director of Snehabhavan Special School, Kottayam. Due to his declining health, Sebastian moved to Christ Hall in 2018 where he remained until his final journey.

In 1985, he had a severe attack of Guillain -Barre Syndrome. As a result, 60% of his body became paralysed. He was put in a wheelchair. But that was not a hurdle to his apostolic zeal. Sebastian became busy as the Director of the Special School, as the coordinator of a Community-Based Rehabilitation (CBR) programme for 800 disabled persons, as a counsellor, spiritual father and retreat director.

Sebastian was able to help thousands of people through Snehabhavan ministries. As part of the CBR programme, many Self Help Groups of People With Disabilities (PWDs) were formed in different panchayats in Kottayam district. To uplift these PWDs, various training programmes in leadership, soft skills and personality development were organised with the support of benefactors and funding agencies. He worked tirelessly for the rights and reservations of persons with disabilities both in state and local level by collaboration, networking and advocacy. It was the golden age for Snehabhavan.

Sebastian was a compassionate listener. The Jesuits, members of other religious orders and congregations and collaborators could find a shoulder to lighten their burdens in Sebastian.

He was a man of prayer and by his way of life, he has inspired so many people. He was a true messenger of Christ who identified himself with the poor and the underprivileged. Sebastian broke his life for the disabled and the mentally challenged children. Indeed, he was an inspiring and daring wheelchair missionary who lived



Sebastian used to take Suffering with peace of mind and a smiling face. Perhaps, he considered them as a means to love and serve his Master. Hence, he showed an exceptional ability to manage physical weakness with grace, love and courage. As a result, some of his friends used to say that one day he would become the patron saint of the differently-abled persons.

his priesthood to the fullness by hearing confessions and offering the Eucharist.

Sebastian used to take suffering with peace of mind and a smiling face. Perhaps, he considered them as a means to love and serve his Master. Hence, he showed an exceptional ability to manage physical weakness with grace, love and courage. As a result, some of his friends used to say that one day he would become the patron saint of the differently-abled persons.

Honouring his meritorious service for the underprivileged, the Catholic Health Association of India and Liliane Foundation bestowed on him 'Disability Award 2019'.

Let him celebrate his Sacerdotal Silver Jubilee with angels and saints in Heaven.



Sanjay Jain principal@ilslaw.in

Pax Lumina 2(6) / 2021 / 27-30

The Transformation of People with Disabilities

et me first congratulate LIPI, the Indian Social Institute (ISI), Delhi and the Peace and Reconciliation Network of the Jesuit Conference of South Asia on bringing out a special issue-PAX LUMINA, dedicated to the rights of the disabled. Since the articles in this magazine have been written in an accessible, non-technical and easy language, it would go a long way in raising awareness about the potential of people with disabilities (PWDs).

In this article, I would like to highlight the changes that occurred in India in response to the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). I will also shed light on problems arising out of these changes. After the ratification of UNCRPD in 2007, in India, a long-drawn-out process began to bring the Rights of Persons with Disability Act, 1995 in line with the Convention. Several public hearings on various drafts of the revised legislation took place throughout India and ultimately, based on consensus, the Rights of Persons with Disability Act, 2016 (RPWD Act, 2016) was enacted by Parliament.

Some of its main features are:

(a) A multi-fold increase in the number of disabilities to be covered by this Act. The 1995 Act covered only seven disabilities whereas, the RPWD Act covers twenty one disabilities. Moreover, this law also provides

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discretion to both the central and state governments to add new disabilities thereby recognising the idea that the disability is an evolving concept requiring the inclusion of some and exclusion of others with time.

(b) Unlike the 1995 Act, the new Act advocates a rights-based model and does not fully endorse the notion of locating disability in the human body. In other words, there is a paradigmatic shift in this law from a medicalised and individual-based model to human rights. Thus, all the basic human rights i.e. the right to non-discrimination on the ground of disability, accessibility, equality before the law and equal protection of the law, legal capacity, and reasonable accommodation has been guaranteed to every person with a disability without stipulating any threshold.

Only affirmative action programmes and schemes like reservations are confined to the threshold of severe disability i.e., where disability is more than 40% and where the same is defined in non-measurable terms. The threshold of percentage for catering high support needs has been stipulated as 80% or more.

(c) There is an explicit provision recognising the legal capacity of every person with a disability and guarding against the abhorrent idea of substituted decision-making. (d) The Act also clearly calls for the espousal of principles of reasonable accommodation, accessibility, and universal design. With the incorporation of the principle of reasonable accommodation in section three and linking it with non-discrimination, this is a big leap towards the promotion of substantive equality.

In other words, there has to be a focus on equality of result rather than equality of opportunities. The principle of reasonable accommodation is also an important addition to the Welfare Legal Regime of India because it drives the idea of individualisation of justice.

No longer does the justice strategy for persons with disability have to be general and one size fits all. Rather, the legislation seeks to address individual cases through the recognition of the principle of reasonable accommodation with a rider that does not amount to undue and disproportionate burden.

There has to be a focus on equality of result rather than equality of opportunities. The principle of reasonable accommodation is also an important addition to the Welfare Legal Regime of India because it drives the idea of individualisation of justice.

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(e) The Act also recognises the right to life and dignity and also calls for communitybased rehabilitation of PWDs thereby countenancing the view that the disabled are not 'others', rather they are part of the same society in which the people with an able body can live. In other words, this legislation challenges the idea of ableism and calls for the embracement of pluralism thereby promoting diversity and fostering diverse humanity.

(f) The Act has also put in place a monetary mechanism by way of State and Central Advisory Boards and provisions for the appointment of Chief Commissioner of Persons with Disability at the Centre and Commissioner of Persons with Disability in all the States. There is also a provision in the constitution of special courts to try the offences under this Act.

All in all, the Act is a major advancement over the 1995 Act and has the potential to make a marked difference in the lives of PWDs. However, the major roadblock is complete neutrality, pessimism and a lack of enthusiasm on the part of the government for its effective implementation.

To give two examples: none of the States in India has yet enacted rules for the implementation of this Act, since most of

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the provisions are skeletal. Without their concretisation by way of rules, the former would look like paper tigers. Secondly, none of the States, including the central government, has shown any zeal in appointing Commissioners and Chief Commissioners for Disabilities.





Even if in some States, Commissioners have been appointed, the appointments are by way of additional charge and ad hoc in nature. Mostly, the tenure of a Commissioner in States is not more than three to six months. The sorry state of affairs vis-à-vis implementation of this Act exemplifies how otherwise good legislation may be spoiled or made sterile. It is high time for the non-governmental organisations and disabled people's organisations to raise their voices against this apathy by the Central and State Governments and put pressure for immediate action to enact necessary rules for the implementation of the RPWD Act, 2016.

The judicial approach

During this dampening time, the approach of the judiciary has been activist though in a sporadic manner. Recently, in 'Vikash Kumar v. Union of India', Justice D.Y. Chandrachud categorically held that basic human rights guaranteed by the Act including the right to avail scribes being all-pervasive in scope cannot be confined only to the persons with benchmark disabilities.

In another important judgment, 'Patan Jamal Vali v. State of Andhra Pradesh', Justice Chandrachud held that to evaluate the vulnerability of women with disabilities due to violence, we should guard against de-segregated analysis merely by focusing on the disability of the victim. He said that to have a full picture, we have to consider how gender and caste intersect with disability in compounding and pathologising the nature of discrimination, prejudice and violence.

This insight may go a long way in transforming the rights of disabled women. In yet another judgment delivered a few weeks ago, the Supreme Court has directed the Centre to stop playing hide and seek and implement Section 34 of the Act in respect of reservations in promotions. The court has given a time of four months to the Centre to evolve modalities for availing this important right to PWDs.

To epitomise, it would be anachronistic to assume that the journey of RPWD has been completely stagnant. PWDs have achieved a few milestones through the legislature, executive and judiciary. Normatively, the present legal regime is much better compared with what it was in 1995. Judiciary has also contributed, though in bits and pieces, in raising the pitch of this theme.

However, it has not been able to invoke substantive doctrines like transformative constitutionalism, constitutional morality and the basic structure of the Constitution while mediating with the rights of PWDs.

However, as an optimist, I hope that sooner than later, disability legal studies become a part of mainstream jurisprudence. I would also explore collaboration in this connection with Indian Social Institute (ISI-Delhi) because it has the tenacity with its extensive network with thousands of NGOs and as one of the NGOs with UN consultative status, to make a difference in the lives of PWDs.

The author is the Officiating Principal at ILS Law College, Pune, and a disability rights activist.



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Autism: When all Areas of Development are Affected

he word Autism means 'in one's world'.

The Ukrainian American psychiatrist Leo Kanner first coined the term 'Infantile Autism' in 1943 when he reported a series of eleven children whose problems had started before the age of two years. His observations and descriptions fit very well with the present-day concept of autism.

However, we know now that the presentation can be more varied, and hence the title 'Autism Spectrum Disorder' is used to describe the condition. Since almost all areas of development are affected, it was also called 'Pervasive Developmental Disorder'.

Several names were used to identify subgroups of the condition in the past. A simple way of looking at this would be to consider the milder forms to be called Asperger's Syndrome; the most severe as Autistic

Today Autism Spectrum Disorder is considered a group of neurodevelopmental disorders that causes delays in the development of socialisation, communication and cognitive skills.

25 Pax Lumina 2(6)/2021 Disorder; and the middle group referred to as Pervasive Developmental Disorder.

Today Autism Spectrum Disorder is considered a group of neurodevelopmental disorders that causes delays in the development of socialisation, communication and cognitive skills. Since the onset is early in life all areas of development tend to be affected over time.

The condition usually comes to the attention of parents or others around the age of two or three years, especially when there is a delay in speech development, or the child does not respond when spoken to, or when there is a loss of speech which the child had achieved.

All symptoms may not be present in all children. As the child grows some of the symptoms may fade away, but new symptoms may develop. Motor development, by and large, is normal in most children.

Because of the variability of symptoms and their severity we still tend to use terms to identify these differences. For example, 'high-functioning autism' is not an official medical term or diagnosis. Some people use it when they talk about people with an autism spectrum disorder who can speak, read, write, and handle basic life skills like eating and getting dressed. They can live independently. They still have difficulties with communication and social interaction. They may have difficulty in making friends and in making eye contact. Others might find their repetitive habits, and orderly and routine actions quite odd. Some will do well in school but others may find it overwhelming.

In children with more severe autism, symptoms will be more obvious – including a preference for being alone, resistance to being cuddled or even touched, engaging in repetitive movements or actions, unusual insistence on routine, repeating words or phrases, laughing or crying or being Though autism is a medical diagnosis, much of the interventions at present are in the home and educational settings. Training should begin at the earliest opportunity and should take place both at home and at school.

distressed for reasons which others cannot understand.

What causes autism? There is no definitive answer. Genetic factors do play a role – other family members may have autism or developmental delays or disorders. Also, other genetic disorders like Fragile X syndrome, Tuberous Sclerosis and Down Syndrome may be present in the family. Environmental factors such as problems affecting pregnancy including certain infections and fetal distress are also associated with autism.

The reasons for consultation:

Parents often come with concerns as early as when the child is 12 to 18 months old.

- Poor social interaction may be noticed by parents, other family members or teachers.
- Delayed speech, loss of acquired speech, making odd sounds

- Poor eye-to-eye contact
- Intolerance to certain sounds, bright lights or colours – child closes eyes or ears or begins to scream
- Regression from previously attained language, social or play skills
- Schools refer to poor socialisation, poor scholastic performances and strange behaviour.

Several medical and behavioural difficulties may be associated with autism.

- Epilepsy is found in 20–35% of children with autism.
- Many children are fussy eaters. They may not like to touch sticky or mashed food; testing the texture or smell of the food before eating; dislike for hard eatables.
- Many children suffer from constipation which may need treatment.
- Pica-eating inedible things like mud or pebbles
- Compulsive eating
- Malnutrition
- Sleep difficulties like day-night reversal; delay in falling asleep
- Attention deficit hyperactivity disorder
- Disruptive behaviours like temper tantrums, aggression, running out.
- Emotional problems anxiety or fear; clinging; sadness and crying due to depression; frequent fluctuations in mood
- Obsessive-compulsive disorder



 Psychotic behaviour – smiling, talking to self, anger outbursts, disorganised behaviour

At a consultation, a detailed medical and behavioural history is collected. Tests will also have to be done to assess visual and hearing impairment. Tests may also need to be done regarding metabolic disorders. Many children need an EEG.

Clinicians will need to rule out other diagnoses like elective mutism; specific language disorders; intellectual disability; delays or disorders of global development or coordination; hearing and visual defects; regression caused by an encephalopathy; and malnutrition due to any reason.

Treatment

Though autism is a medical diagnosis, much of the interventions at present are in the home and educational settings. Training should begin at the earliest opportunity and should take place both at home and at school.

Many skills are taught at home – eating, brushing the teeth, bathing, toileting, and sleeping. Autistic children learn these best in a structured, predictable environment. They should feel secure and open to learning without anxiety.

Special teaching at schools often adopts one or more specialised techniques like:

 Training and education for autistic and communication handicapped children, a well-organised school environment, strict schedule, visual teaching aids, and short and clear instructions. These need to be individualised depending on each child's needs.

 Applied Behavioural Analysis. Among other techniques uses rewards for positive behaviour

 Picture Exchange System is useful for training in activities of daily living

Many children will have coexisting medical, neurological and psychiatric conditions which need to be investigated and treated. Such treatment will reduce the distress experienced by the child and the family, and help the child to better participate in the training.

There are effective treatments available for epilepsy, sleep disorders, anxiety, phobia, depression, Attention Deficit-Hyperactivity Disorder, aggressive and self-injurious behaviours, as well as psychotic symptoms. Medical treatments may also need to be done for long periods to achieve lasting improvements at the lowest possible doses of the appropriate medications. In conclusion, autism is a neurodevelopmental disorder. Children with autism will need help in every stage of life, and training plays a major role in the developmental stages. Early detection and intervention are essential.

Working with children or adults with autism involves dedication and commitment from parents, teachers and other professionals. There are many such parents and others who go largely unnoticed in our society. Many more teachers and professionals need to get involved in the world of autism.

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This is a journey of someone who grew up in the neediest of slums but was introduced in a small way to a then-vague term known as peace, but which slowly inculcated in me a search for its true essence.

Peace Promotion in the Slums

he slum community consists of people who live in informal settlements within cities and have inadequate facilities. Working among such people who have strong survival instincts is challenging but close to my heart.

How can we expect 'peace' in a set-up that is so ruthless and unequal? How can we expect 'positive change' in a set-up that is so negative and restricted? Being a survivor from a similar community, I am convinced that if I can change for the better, so can such communities. The ones who hurt can become healers and the ones who wage war and violence can become harbingers of peace and harmony.

Being a survivor from a similar community, I am convinced that if I can change for the better, so can such communities. The ones who hurt can become healers and the ones who wage war and violence can become harbingers of peace and harmony.

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A peek into the life of slum dwellers

When we try to picture a slum, we think of noise, violence, garbage, less-educated people, verbal and physical abuse, and less space. All of these are true and more. However, there is another side. People are generous, welcoming, and openly share their happiness, struggles and sadness.

In a slum one can never feel alone, as there is always someone for you. People do fight, but they also celebrate together. People earn less money but they share their food. People are less educated, but they know how to respect each other. Because of lack of space, children do not have playgrounds, so they play on the road, and have fun, dangerous as it may be.

Verbal and physical abuse is very common, but the love and affection one gets are priceless. When you look closely, you will find people struggling to fulfil their daily needs. Standing in long queues to use latrines and bathrooms, waiting for their turn to fill water for household chores, children waiting to have a bath before going to school, mothers busying themselves at household chores that they can't take care of themselves, are common features of a slum-dweller. It is indeed the survival of the fittest where everyone is on the run to meet basic human needs.

Intervention through peace promotion

It is expected that when so many people are living together in a limited space and struggling to complete their day-to-day activities, there will be misunderstandings and complaints against each other. In this rat race, being physically exhausted and mentally frustrated is common. Showing frustration to family members and others is a lifestyle. It is easy to show compassion and generosity when one has enough and easy to be at peace within and without when one's surroundings are peaceful. But living in such challenging communities may not be conducive for peace. It becomes an impossible virtue to achieve.

Since we already know that people in slums are less educated and thereby less aware of their rights and entitlements, the responsibility falls on social workers and activists to help build up their resilience and capabilities. It is a long-drawn-out process, but we have to start somewhere by introducing the concept of peace. If not the present generation, the next generation will surely imbibe the values of peace and social harmony. I was a school student when I was first introduced to an agency working at community and peace-building. It was not easy. I was critical of the concept, but with time not only have I realised its importance at the micro-level, but also at the macro level. I built my capability by attending peace-related workshops, seminars and being associated with organisations working for peace. I have learnt over the years the seeds of peace need to be a part of any social issue we may be working at.

The organisation I am associated with has Peace Promoter Teams or a Children's Parliament, where youngsters are selected, trained, and encouraged to play an important role in everyday issues of the communities they are part of. These issues include domestic violence, child marriage, dowry or alcoholism. They are taken to the judicial system or to the local informal leaders who try to solve the problems amicably.

Steps in building peace promoters or children's Parliament

1. Identify local adolescents with leadership skills

- 2. Introduce the concept of peace
- 3. Test their interest and skills through simple tasks and assignments
- 4. Dialogue with them giving them examples of violence, injustice and social evils
- 5. Conduct workshops and training to help them come up with solutions
- 6. Formally connect them to local club authorities of their communities
- 7. Encourage and recognise their role in promoting and practising peace
- 8. Help them get formally recognised as peace promoters

This is a journey of someone who grew up in the neediest of slums but was introduced in a small way to a then-vague term known as peace, but which slowly inculcated in me a search for its true essence. As I grew from a young boy to an adult, I allowed myself to give peace a chance and to look beyond the confines of disharmony, hatred and want.

I am limited in my resources but have not allowed these societal limitations to limit my potential as a human being to be resilient, kind, giving and tolerant. If I could look beyond my circumstances, any slum dweller can do the same. So I am now an ardent believer in Christ-like peace, that liberates, is tolerant, able, strong-willed and which is possible even in a so-called hatefilled world. I have started small with the concept of peace promoter teams.

Are you willing to join me to promote peace in your communities?

The author hails from Calcutta. He participated in Peace Studies programme jointly organized by Centre for Peace and Justice-XLRI Jamshedpur and LIPI, Kochi from July-October 2021



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Pax Lumina 2(6) / 2021 /38-39

The Phenomenal Rise of Indian Paralympians

nspirational, incredible and indomitable. This is how India's performance at the recently concluded Paralympics Games 2020 in Tokyo can aptly be described. India won 19 medals: five golds, eight silvers and six bronzes. In all, 54 athletes came to Tokyo and 17 of them left with medals. For the first time, the attention in India turned to Paralympics sports. This was India's finest outing at the Paralympics and eclipsed the previous best of four medals at the Rio de Janeiro edition in 2016. Incidentally, the disabled represent 2.2% of India's population.

There are many firsts to celebrate.

The 19-year-old Avani Lekhara became the first Indian woman to win a Games gold (10m air rifle) and later added a





bronze in 50m rifle 3 positions to ensure that her name would now be part of every India-centric Paralympics trivia. The 39-year-old Singhraj Adana, on the other hand, won a 10m air pistol bronze and 50m pistol silver to ensure that India had more than one double medallist in the same Games.

There was the first medal in archery through Harvinder Singh (bronze), impaired after wrong medication for dengue and the first medal (silver) in table tennis by waist-down paralysed player Bhavinben Patel, along with two gold medals in badminton by Pramod Bhagat and Krishna Nagar.

Though the Paralympics Games were first organised under the aegis of the International Stoke Mandeville Games Federation in Rome in 1960, India made its debut only in the 1968 Tel Aviv Paralympics, where the contingent of 10 athletes failed to grab any medal.

Murlikant Petkar made a 'golden' breakthrough at the 1972 Heidelberg Games when he set a world record at 37.331 seconds in the 50m freestyle swimming. After missing out on two Games thereafter, India made a strong comeback in 1984 by winning four medals.

Joginder Singh Bedi bagged three out of the four medals - a silver in the men's

shot put L6 event, a bronze in the javelin L6 event and a bronze in the discus throw L6 event. For the fourth medal, Bhimrao won silver in the L6 javelin throw.

The success of 1984 was followed by a 20-year long drought of medals. Devendra Jhajharia ended it with a gold medal in the 2004 Athens Paralympics. There was another medal from Rajinder Singh, who won a bronze in the 56-kg category in powerlifting. Beijing proved out to be a disappointment for India. But the Indian contingent bounced back with two medals in the 2012 London Paralympics and a record-matching fourmedal haul in the Rio Paralympics.

This phenomenal performance in Tokyo will remain inscribed in the memories of all Indians for years to come. If we look at the pattern along which we have progressed since 1968, there have been inconsistencies in performance. For whatever reasons, we have failed to build upon instances of excellence. For every crest, there has been a dip. At this point, we need to ensure that the momentum doesn't die down. The success and pride our para-athletes have brought to the nation can be gauged through accolades and medals. But their excellence and spirit are beyond the purview of shining metals.

International

Concentrate on things your disability doesn't prevent you doing well, and don't regret the things it interferes with. Don't be disabled in spirit, as well as physically.

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Living with Disability in the UK

As we travel around in Various cities in the UK or visit different offices, educational institutions, hospitals, entertainment places, religious buildings, hotels, streets, and car parking places we can observe a friendly environment, where the infrastructure and facilities are adapted to allow people with disabilities easier access without much difficulty.

ast summer, in the most challenging situations of the COVID pandemic, the most inspiring disabled athletes from around the world, including from Great Britain (GB), gathered in Japan to encourage the whole world. The British Paralympic team won a total of 124 medals, including 41 golds, placing GB second in the Tokyo Paralympics medal table.

The Games also saw Dame Sarah Storey become Britain's most celebrated Paralympian ever as she secured her 17th gold medal. I found all the athletes so inspiring, and their valuable personal stories may help change our perceptions about people with disabilities.

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As we all know, the Paralympic Games are a major international multi-sport event for athletes with physical disabilities or intellectual impairments. This includes athletes with mobility disabilities, amputations, blindness, and cerebral palsy.

British athletes have come together from all parts of the UK and collectively delivered a lesson in the art of resilience, passion and ambition resulting in extraordinary moments which have uplifted and inspired the nation. Through their performances, we have seen socially conscious people of immense talent and character display the incredible power of sport to lift a nation and bring optimism to the world.

In a message, Her Majesty the Queen offered her 'warmest congratulations' on their 'enormous success' at the Games. She appreciated the team by saying the "commitment, dedication and adaptability shown by you, and your support teams,

n my professional research field for promoting mental health and wellbeing, I have come across many inspiring people with disabilities in various organisations in the UK and they are working together to create a society where disabled people have equal power, rights and equality of opportunity. during the exceptional circumstances of the last 18 months has been inspirational. Your performances have lifted the nation and your triumphs have been celebrated by us all."

This remarkable message reflects the country's support for people with disabilities. As we travel around in various cities in the UK or visit different offices, educational institutions, hospitals, entertainment places, religious buildings, hotels, streets, and car parking places we can observe a friendly environment, where the infrastructure and facilities are adapted to allow people with disabilities easier access without much difficulty.

All these places show how seriously the various requirements of disabled people were considered and recognised, including those with sensory and cognitive impairments. We can also see reserved spaces in taxis and smaller buses to accommodate a passenger in a wheelchair. In addition, disabled people have specially-designed bathrooms and restrooms.

These facilities and supporting systems for disabled people influenced me to admire this country's common policies and concerns for people with disabilities. Today, this evidence demonstrates how much western society respects and values that every individual with a disability has the same rights and needs as everyone else.

History shows today what they have achieved, and all the necessary support has been provided because of their long fight for their rights as one community. But globally, freedom and equality are far from the reality for the more than one billion people with disabilities, who make up 15% of the world's population.

According to the World Report on Disability, the number of people with disabilities is increasing everywhere. Despite being 'the world's biggest minority', people with disabilities are often forgotten. It is an important time for us to come together to recognise their needs and to be with people with disabilities to promote respect for their dignity and fundamental rights.

In my professional research field for promoting mental health and wellbeing, I have come across many inspiring people with disabilities in various organisations in the UK and they are working together to create a society where disabled people have equal power, rights and equality of opportunity.

One of the organisations, Disability Rights UK, is the UK's leading organisation led by, run by, and working for disabled people. This organisation works with other disabled people's organisations and the government across the UK to influence regional and national change for better rights, benefits, quality of life and economic opportunities.

We all are grateful to Stephen Hawking, who lived in this century as one of the most remarkable human beings to have graced this planet with true inspiration to the disabled and abled.

I have chosen three people with disabilities to understand more about living life with a disability in the UK.

Dr. Frances Ryan is a journalist, broadcaster and author and is a wheelchair user based in Nottingham, England. She writes a weekly column for the UK newspaper,





'The Guardian,' typically about disability, poverty, education, health, austerity and politics and all types of inequalities. She is the author of 'Crippled: Austerity and the Demonisation of Disabled People' (2019, Verso Books).

Dr Ryan was highly commended as Specialist Journalist of the Year at the 2019 National Press Awards for her work on disability and shortlisted for the Orwell Prize 2019. She wrote about one of the world's most famous British scientists and disabled people, Stephen Hawking (1942–2018).

Professor Hawking was a brilliant theoretical physicist who revolutionised our understanding of time and space. He also shifted societal perceptions of people with disabilities and used his fame to advocate for disability rights.

In an opinion piece for The Guardian, Ryan describes what Hawking meant to her:

"Growing up disabled in Britain, I didn't have many role models. There are hardly any statues of disabled leaders, no great lives with a chronic disability documented in the history books. As a child, it is easy to believe that disabled people have never existed and when they did, it was as cripples to be pitied or burdens on society. In Hawking, we had a figure – brilliant, witty, kind – who confounded the negative stereotypes and the low expectations so often forced on those of us with a disability."

We all are grateful to Stephen Hawking, who lived in this century as one of the most remarkable human beings to have graced this planet with true inspiration to the disabled and abled. In an interview with The New York Times, Professor Hawking said: "My advice to other disabled people would be, concentrate on things your disability doesn't prevent you from doing well and don't regret the things it interferes with. Don't be disabled in spirit, as well as physically."

Given current situations of post-COVID and post-Brexit, it is understandable that many disabled people feel alarmed, and they have been pushed more into poverty and potentially social isolation.

Prof. Hawking was diagnosed with Amyotrophic Lateral Sclerosis (ALS) when he was 22. As ALS progresses, the degeneration of motor neurons in the brain interferes with messages to the muscles in the body. Eventually, muscles atrophy and the muscles' voluntary control is lost, which gradually paralysed him over the decades. However, he reached the height of his field while being a wheelchair user and communicating through a synthetic voice.

One of his short video messages got all the world's attention which he delivered with synthetic voice technology in the UN Educational, Scientific and Cultural Organisation (UNESCO) conference, titled 'From Exclusion to Empowerment: The Role of Information and Communication Technologies (ICTs) for Persons with Disabilities, on November 24-26, 2014, in New Delhi.

Here is an extract from Prof. Hawking's message:

"Can you hear me? I am delighted to address the delegates of this UNESCO conference in India to promote the human rights and fundamental freedoms of persons



with disabilities and their empowerment through information, communication, and technologies.

I feel a responsibility to speak for others who have no voice. I have not been lucky to contract ALS, but I have been lucky to have this help. I want to use my high profile to raise awareness of issues around disability and communication.

"I want to speak up on behalf of people who live their whole lives in that state. I hope that the kind of technologies I have trialled and helped develop will become easily and cheaply available to all who need them. We need to make sure this technology becomes available to those who need it so that no one lives in silence. Please listen to me, I speak for the people who can't hear."

Stephen Hawking not only changed the way people thought about science, but he also changed the way people perceived disability.

Alex Taylor, who suffers from cerebral palsy, is a freelance journalist interested in current affairs, social issues, the arts and disability. He advises the leading children's charity in the UK, the National Society for the Prevention of Cruelty to Children as a young ambassador for disability. People with disabilities in the UK have had a strong welfare state that has given them a real safety net: from the National Health System, benefits to pay for the extra costs of disability, and increasing support for the right to live independently.

However, over the past decades, with the government's various financial austerity measures, these social security systems for people with disabilities have been affected. Given current situations of post-COVID and post-Brexit, it is understandable that many disabled people feel alarmed, and they have been pushed more into poverty and potentially social isolation.

These tendencies of cutting back social care and security systems and the support of disabled people are global issues facing the disabled community everywhere. These inspiring people invite each of us to join with them to help protect the rights of people with disabilities globally.

The author is a Jesuit and a Counselling Psychologist Research Trainee at Glasgow Caledonian University, School of Health and Life Sciences, UK. He holds an MSc. in Child & Adolescent Mental Health from King's College, London at the Institute of Psychiatry, Psychology and Neuroscience and an MSc. in Clinical and Health Psychology from Bangor University, UK.



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Enabling the Differently-abled

Navjyoti: A Thriving Day-Care Centre for the Intellectually Challenged Children in Kathmandu

wo days after the devastating earthquake in 2015, Supridhi Subedi walked into the Navjyoti Centre campus in Kathmandu along with her mother to find out about her principal and the school where she was studying. She had urged her parents to visit the school to find out if everything was all right.

Supridhi joined Navjyoti at the age of nine. Since she was not able to study and cope with her peers, the parents had brought her to the centre. Navjyoti Centre is her second home. She enjoys the company of her friends. She is the boss in her home. The family members have to listen to her and meet all her demands. Thus, she claims her space and role as a daughter. The Sisters of Charity of Nazareth (SCN) run the Navjyoti Centre, a day-care centre for differently-abled children. The aim is to provide an atmosphere of love, acceptance and personal care. The nuns impart basic education, social competence and vocational skills as far as their capabilities permit. They encourage the children to take up jobs and to live with respect and dignity.

On August 25, 1978, Fr. Adam Gudlefsky, a Mary Knoll priest from the USA opened a small centre for the mentally retarded children in Kathmandu with three boys and two girls.

This unit marked the beginning of people changing their attitudes towards mentally

handicapped children. Instead of hiding them away, they were now given a chance to receive domestic, personal and social education.

In 1983, before leaving for the USA, Fr. Adam handed the responsibility of running the centre to George and Mary Cheru. In February, 1988, George and Mary left for their native place. Thereafter, the SCN sisters took charge. From then on the Centre came to be known as Navjyoti Centre.

The children are from the age group of 6 to 27. They are divided into groups according to the degree of their handicap so that each child's learning ability can be understood and developed in the best possible manner. Each class has five to ten students. Preference is given to the poor, especially girls.

The children are engaged in self-help skills, language study, arithmetic, drawing, painting, singing, dance, art, craft, yoga and meditation. Children enjoy various indoor and outdoor games.

Different therapies like speech, music, physiotherapy, dance and relaxation help the children to be efficient and gain selfconfidence.

The use of sensory and cognitive classrooms helps to improve their attention and concentration besides improving their imagination and creativity. Swimming, wall climbing, cooking, shopping and gardening help to improve their capabilities.

When it comes to sports and games, some of the children have excelled at the local and national levels.

In the 1980s, Chirendra Raj Satyal gave coaching to the children. He led the first team of athletics to the USA to participate in the Special Olympics. Following Chirendra, Ganesh Parajuli has taken up the mantle. He has taken the children to different countries. About fifteen students have taken part in

The aim is to provide an atmosphere of love, acceptance and personal care. The nuns impart basic education, social competence and vocational skills as far as their capabilities permit. They encourage the children to take up jobs and to live with respect and dignity.

the Special Olympics. In the 13-member Nepalese team, which took part in the Special Olympics at Abu Dhabi in 2019, four participants were from Navjyoti.

Among them, Ajay Tamang won the gold medal in the shot put, while Kshitiz Baniya and Ishan Shrestha won the silver medal for Futsal. Sunita Sunwar participated in the track events.

Over the years, we have seen a change in the mindset of the people. In the early days, people believed that having a child with special needs was a curse from God or due to the sins of their ancestors. But over the years, because of education and exposure, there is a change in attitude.

They see that the children are unique and have special gifts. They are a blessing to the family. The father of one of our girl students has become the Superintendent of Police. He says that his daughter has brought this blessing to him. There are other parents too who feel the same way.

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Tikeshwori Joshi, the mother of Sushant, says, "I brought my son to Navjyoti at the age of seven. He was not able to do anything by himself. He never established eye contact, and communication was almost nil. I never thought he would be able to take care of himself. But after being in Navjyoti he has improved a lot. He helps me with washing his clothes, cleaning, cutting vegetables, and cooking."

Sushant has learned cycling. The family members were surprised to see him cycling in the village when he went on holiday. He can use the computer for different purposes. He has attended the online class during the lockdown with minimum assistance from his mother. "Now my child is a different person," says Tikeshwori. "This was possible because of the love and individual care he received from Navjyoti. It has made him what he is today."

The centre's hero is Kshitiz Baniya – a blooming artist. Even though he has a hearing impairment, he can manage everything by himself. He is a very good athlete, football player, and dancer. Kshitiz enjoys cooking and playing the guitar. He is excellent at cycling. He helps in the classroom as an assistant to the teachers. The children are engaged in self-help skills, language study, arithmetic, drawing, painting, singing, dance, art, craft, yoga and meditation. **Children enjoy various indoor and outdoor games.**

A few children have been doing part-time/ full-time jobs. They include Sangam Upreti who works in a supermarket, Amit Yogi helps in a nursing home, Naresh Chhetri works in a garage, and Balram Pariyar helps his father Navraj Tiwari, who has a small roadside shop. A number of them are married and lead a family life. Skilled vocational training is the need of the hour and job placement.

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During the lockdown, the parents were handicapped because they did not know how to engage the children in different activities. So, the centre arranged for online classes for those children who had internet facilities. Many learned to use laptops and mobiles. They looked forward to attending the online classes. A couple of them even called the staff before time. The nuns felt proud that some of the students were able to manage the household work when the parents had gone out for work.

The government is emphasising inclusive education. As a result, they are constructing schools with disabled-friendly structures. There are a couple of schools in every district with hostel facilities for special children. They are provided with food and free educational materials. These children study beside the mainstream children. Thus, they are getting an opportunity to interact with them. This makes them feel they are all part of society.

Moreover, it gives opportunities for the other students to love and appreciate the special children and feel a moral responsibility to



take care of them. The differently-abled persons can get an ID card made according to the severity. The government is providing monthly allowances NPR 4000 for those who are severely disabled while for moderate and mild categories they receive a sum of NPR 3000 and 2000 respectively.

To add a personal note, my work among the intellectually disabled is an option. In 2013, when my Superior asked me to discern for a new mission, I opted this. Having specialized in psychiatric nursing I was familiar with the different categories of persons like Down syndrome, Autism, Cerebral Palsy, Mental retardation etc. I had realized that what is mostly needed for these children and their parents are acceptance and love. I could understand the parent's struggles and frustrations as I had the experience of having a differently-abled person in our family (my cousin). This helped me to be empathetic towards the disabled. Unfortunately, he suffered an unnatural death. This further affirmed my ministry with differently-abled special children.



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Enhancing the Quality of Life of the Differently-abled in the US

y mother died at 94. She spent the last one-third of her life as a physically disabled person after suffering a brain aneurysm in her early 70's. After the aneurysm, her remaining years were wheelchair-bound. She spoke with difficulty, was unable to write, and gradually became blind.

I was her primary caregiver for the remaining 10 years of her life.

Unless you are disabled or a caregiver, you don't fully appreciate the challenges disabled individuals face living in a society of ablebodied people. They face stairs, sidewalk curbs, doors, bathroom facilities, buses, and cars. They have to always communicate their needs to others. These are activities that the able-bodied person takes in stride.

As a caregiver, I learned the importance of structural conveniences required by US governmental laws designed to provide access for all. Regulations require public buildings to provide ramps for wheelchair access, cut-outs in sidewalk curbs, public facilities to provide large bathrooms with bars around the toilets and showers, and handicap parking close to buildings. Early boarding on aeroplanes, wheelchair platforms in concert halls, and first-in-line spots for special events make it easier for the disabled to enjoy the benefits of living in the US.

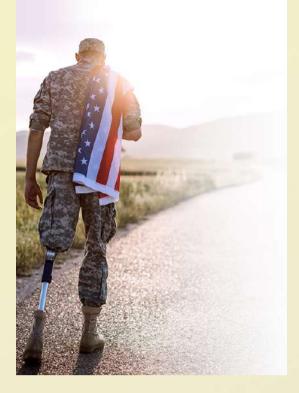
The approach of the government and society in caring for the disabled is based on the Christian ethic of dignity and respect due to each individual, regardless of their abilities. Our Constitution says that 'all men are created equal, endowed by their Creator with certain inalienable rights ...' Providing the disabled with equal access is an issue of civil rights, not charity. Unless you are disabled or a caregiver, you don't fully appreciate the challenges disabled individuals face living in a society of able-bodied people.

The American governmental laws and regulations to address the challenges faced by the disabled started as individual, community efforts. In the 1900s, grassroots efforts developed into national campaigns to fight for fair employment, assistance for retarded children and the rights of the disabled. These were championed by presidents including Harry Truman and John F Kennedy.

The most far-reaching law, the Americans with Disabilities Act was passed in 1990. It prevents discrimination of people with disabilities in areas of employment, communications, public accommodation, and access to state and local programmes and services.

Not only can disabilities be physical, but also mental. We live in an increasingly complex and rapidly changing world. This includes emphasis on using computers to negotiate daily activities. Not everyone has access to a computer or is computer literate.

On a recent trip, I experienced how airlines are increasingly using QR codes, iPhones, and messages sent by texts to keep the traveller aware of schedule changes. It can be impossible for an individual who has mental challenges to travel without support.



This limits their opportunities and options. My mother was incapable of handling these kinds of challenges. I handled them but not everyone can rely on someone to care for them. I also found during my years of negotiating my mother's wheelchair that there is another feature of how our society treats the disabled. It boils down to whether a society values and expresses, in action, the value of each individual.

One year I took my mother to see the White House in Washington. When we entered through the gate, we were greeted warmly by one of the White House staff. Since she was in a wheelchair and there were stairs to be negotiated in the regular tour, the man personally escorted us on a separate tour. We were able to visit the kitchen and take a ride on the private presidential elevator. We felt special.

The mental and physical difficulties faced by my disabled mother were lightened by the staff endorsement that she was someone whose disability made her unique and appreciated. Also, there were many occasions when strangers saw our difficulties and stepped up to help. My simple effort of getting the wheelchair in and out of the trunk of the car was often met with offers of help from sympathetic observers. Many challenges remain to fully integrate the disabled into our society. Challenges include equal employment, accessibility to travel, educating society about the challenges faced by the disabled, and representation in the media and politics. It is the challenge of recognising that these individuals have inherent dignity, can be productive citizens, and that they have a right to concrete expressions of respect, including equal access.

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Joan lives in Albuquerque, NM, USA and has advanced degrees in Biology (Ph.D.) and Theology (MTS). She is also a Board Certified Catholic Chaplain.



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Endosulfan, the Pesticide that Sprayed Misery on Villagers



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n 1998, a group of villagers from the Kasaragod district in Kerala approached Dr. Ravindranath Shanbhogue, the founder of the Udupi-based Human Rights Protection Foundation (HRPF). They handed him a note, written by Dr. Mohan Kumar of Enmakaje village.

The doctor wrote, 'More than 100 residents are suffering from cancer, asthma, and schizophrenia. In almost every household, some children are suffering from growth defects or neural disorders such as epilepsy, cerebral palsy, and memory loss. Several children have been born with congenital physical abnormalities.'

Dr Kumar wanted to know whether the HRPF could find out the exact cause. Immediately, Dr. Shanbhogue proceeded to the village along with a group of postgraduate student doctors from the orthopaedic and paediatrics departments in Udupi.

In a preliminary survey, it was found that 23 out of 103 persons had cerebral palsy, 20 were epileptic, and 43 were suffering either from physical abnormalities or from various psychiatric disorders. Seven women had endocrine problems. The reports collected from the district government hospital and local nursing homes revealed that 46 residents had succumbed to cancer while seven committed suicide in the preceding five years. Three cancer patients who were still alive were immediately shifted to the Kasturba Hospital Manipal for further investigation.

Curse of the Bhootha 'Jatadhari'

The HRPF investigators could not understand why there was no outcry and no awareness regarding this tragedy among the people. The HRPF team members observed that most of the villagers were illiterate and poor. They believed that these ailments were due to the curse of a local ghost called 'Jatadhari'. Other than praying to the ghost for mercy the villagers could do nothing.

Soon, many interesting details became known. In 1981, when four calves were born with additional and abnormal limbs, Shri Padre, a local journalist published several articles, demanding an investigation by government agencies.



Dr. Shanbhogue, the Crusader

Dr. Ravindranath Shanbhogue is a human rights activist, environmentalist and social worker, who sincerely dedicated himself to the cause of poor and voiceless populace affected by diseases caused by the exposure of Endosulphan in Karnataka and Kerala. Dr. Shanbhogue is a retired professor of pharmacology from Manipal.

Dr. Shanbhogue has launched various media campaigns and conducted public awareness programmes throughout the country regarding the harmful and dreadful use of Endosulphan. Articles published by Dr. Shanbhogue in various periodicals had highlighted various issues of injustice and abuses. He is now dealing with the issues of Endosulphan and human rights at State, National and International levels. He has done tremendous work in the field of Endosulphan and has stayed in Endosulphan affected rows almost 4 years and conducted studies and resources on the victims. He also submitted a comprehensive research report on Endosulphan toxicity initially to the National Human Rights Commissions. In his petition to Supreme Court of India he explained all the havoc created by Endosulphan in Kerala and Karnataka and produced the scientific evidence collected from all over the world. After detailed deliberations, the production, distribution and sale of Endosulphan poison was banned throughout India by the Supreme Court of India on 13.05.2011.

n a preliminary survey, it was found that 23 out of 103 persons had cerebral palsy, **20 were epileptic, and 43 were suffering either from physical abnormalities or from various psychiatric disorders. Seven women had endocrine problems.**

The district hospital records showed that the maximum number of patients admitted to this hospital during the previous decade were from this village. Even though the villagers were suffering from unusual ailments, hospital authorities never bothered to find out the reasons. They sent the reports to the state authorities, which did not take any action.

In 1996, Dr. Mohan Kumar's letter to the editor regarding this problem was published in the Kerala Medical Journal. Neither the government of Kerala nor the health ministry took cognisance of these unfortunate health issues.

Initially, the investigators suspected the contamination of drinking water with heavy metals such as cadmium, chromium, lead, or mercury, as these cause similar ailments. But the water analysis report obtained from a regional laboratory came negative.

Ultimately, a schoolteacher suspected the 'Oushadam' (medicine) that was being sprayed for the past several years on cashew

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plantations in the vicinity. The Kerala Cashew Development Corporation had raised these plantations by destroying 4600 hectares of thick forest. The sole objective was to earn dollars by exporting cashew nuts to western countries.

Nobody knew anything about the medicine that was being sprayed. It took several days for the HRPF team to know the name of the pesticide: endosulfan. It is a molecule belonging to the organo-chlorine group with a wide range of toxic effects, not only on pests but also on animals.

To get more details on the toxic profile and to collect related scientific literature, the team members rushed to the Indian Institute of Science at Bangalore. Within 15 days, more than 200 research papers were collected, which revealed that endosulfan could produce all the ailments seen in the village.

Public outrage against endosulfan

During the first week of December a frontpage article published in 'Udayavani', a Kannada daily, questioned the scientific basis of aerial spraying of the poison using helicopters. On December 26, 2000, when a helicopter was about to spray endosulfan, 50 boys from these clusters of villages went to the helipad and protested against the poison being sprayed.

An officer of the Kerala Plantation Corporation called the police. It was easy for the police to control a small number of protesters. That day more than 600 litres of endosulfan were sprayed.

The next day, all the youths reunited under the leadership of journalist, Sree Padre. Dr. Mohan Kumar, Dr. Sripathi Kejampady and Dr. Subramanya Bhat joined the protest. They demanded that until scientific proof could be shown that endosulfan was not the cause of these unusual diseases, it should not be sprayed. This was the first struggle against the use of endosulfan in India.

Minister in denial mode

In February 2001, Dr. Shanbhogue published a report on the 'Endosulfan Tragedy' in 'Taranga', a popular Kannada weekly, quoting several findings published by world-renowned scientists. The awareness created by this article made the District Collector visit the village. Within a few weeks, more reports appeared in the Kannada and Malayalam press regarding the children with similar ailments from several villages of Kasaragod and Kannur districts. The report revealed that there was a significantly higher prevalence of neurobehavioral disorders, congenital malformations in female subjects and abnormalities related to the male reproductive system in people who were exposed to endosulfan. Even minute doses could result in organic disorders in later life if the exposure takes place during the early developmental phase.

Activists from the environmental organisation 'Tanal' (Shadow) in Thiruvananthapuram rushed to assess the tragedy and to join the struggle. Thanks to the Internet, the reports reached all over the world within a few days. This created a strong public opinion against endosulfan.

Krishnan Kaniamparambil, the then Agriculture Minister, called a press meet to rubbish all the reports that implicated endosulfan.

Meanwhile, the number of victims was increasing day by day.

Focus shifts to Karnataka

In April 2001, the district administration conducted a public meeting at Kasaragod

wherein representatives from affected villages were invited. At the meeting, the minister threatened the journalists that cases would be filed against those who spread 'false rumours' about endosulfan. He suggested that Dr. Shanbhogue and his team continue their research in a cluster of villages near Dharmasthala where the Karnataka Cashew Development Corporation (KCDC) was spraying the same pesticide.

It was a surprise for everyone. Till then it was presumed that endosulfan had caused havoc only in Kerala.

Immediately, the research team rushed to Dharmasthala. The KCDC had raised cashew plantations in 30 villages. A tiny village called Kokkada was selected for house-tohouse search and 13 affected children were found in a single day. Within a week, the number swelled to 250. Every household was found to be severely affected.

The reactions of Karnataka politicians were similar to that of Kerala. Everyone was in denial mode.

ICMR was asked to investigate

The National Human Rights Commission initiated 'suo moto' action on the report entitled 'Spray of Misery', which was published in 'India Today' magazine on July 23, 2001. The NHRC asked some agencies including the Indian Council of Medical Research (ICMR), to submit a report on 'Unusual Illness' produced by endosulfan exposure in the villages of Kasaragod.

The report revealed that there was a significantly higher prevalence of neurobehavioral disorders, congenital malformations in female subjects and abnormalities related to the male reproductive system in people who were exposed to endosulfan. Even minute doses could result in organic disorders in later life if the exposure takes place during



the early developmental phase. By this time the Internet was available. More than 650 research publications by well-known scientists were collected on the subject. Now, there was no doubt that endosulfan was the culprit.

The role played by RTI Act

In 2005, the research team of HRPF got an excellent tool called the Right to Information (RTI) Act passed by the Indian Parliament. Sanjeeva Kabaka, an activist shot more than 300 hundred RTI applications towards KCDC. As per the information received, the KCDC had sprayed more than 450 villages spread over the districts of Dakshina Kannada, Udupi and Uttara Kannada. The team could collect the exact amount of endosulfan sprayed over each village for the preceding 20 years. This gave a clear picture of the poisoning of the soil as well as waterbodies of coastal Karnataka.

During the next five years, volunteers of HRPF, most of them NSS students of nearby colleges, visited the affected villages of the three districts.

By 2010, an exhaustive village-wise list of over 8500 victims was prepared. Repeated requests to the government of Karnataka to provide compensation was ignored. After much persuasion, a 'Day Care Centre for endosulfan victims' was established at Kokkada village. But the manufacturers of endosulfan issued a legal notice to the Government of Karnataka and could get the word 'endosulfan victims' removed from the name of the centre. This indicated that government officials were unaware of the tragedy.

In 2011, Dr. Vandana Shiva, the Managing Trustee of the Navadhanya Trust of New Delhi, came to Kasaragod to participate in a seminar wherein Dr. Shanbhogue gave a presentation on the endosulfan tragedy. Within a few days, Dr. Vandana arranged a seminar at the prestigious India International Centre in New Delhi. She invited all the Delhi-based scientists and legal luminaries. Dr. Shanbhogue attended and gave a presentation.

The very next week, an Application for Intervention was filed on behalf of Navodaya Trust and HRPF in the Supreme Court for banning endosulfan throughout the country. The petition described the havoc caused by endosulfan in Kerala and Karnataka and produced scientific evidence collected from all over the world. After detailed deliberations, the Supreme Court banned the production, distribution and sale of endosulfan throughout India on May 13, 2011.

What should we do to mitigate the suffering of these victims of endosulphan? It is high time we thought of feasible solutions for these lingering problems. **Our objectives should be clearly defined and strategies identified. In any case, their suffering cannot be allowed to continue.**

The HRPF approached the Karnataka High Court for compensation

Since the Supreme Court had accepted that all the unusual ailments found in Kerala and Karnataka were due to the toxic effects of endosulfan, it was easy for Dr. Shanbhogue to demand compensation. In 2013, the HRPF filed a Public Interest Litigation in the High Court of Karnataka asking for compensation for all the victims.

On January 27, 2014, the High Court, in an interim order, directed the government of Karnataka to assess the disability of every victim and compensate accordingly. Now, as per the order, every child suffering a disability above 60% gets Rs. 4000 per month for life. Children with below 60% of disability get Rs. 2000 per month. Apart from this, all the victims get free medical treatment as well as monthly rations.



Victims of Kerala yet to get justice

The sad part of the story is that even though the toxic effects of endosulfan were initially noticed in Kasaragod, the victims are yet to get compensation. They get a meagre amount as a monthly pension. The HRPF made several attempts to get the information regarding the exact number of victims and their percentage of disability from social activists of Kerala. But no help was forthcoming.

To conclude, what should we do to mitigate the suffering of these victims of endosulphan? It is high time we thought of feasible solutions for these lingering problems. Our objectives should be clearly defined and strategies identified. In any case, their suffering cannot be allowed to continue.

The author is currently working as Software Engineer in an MNC and he is a volunteer in an NGO called Human Rights Protection Foundation, Udupi. He is an environmental activist and a promoter of the protection of the senior citizens.



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Architecture for Peace and Harmony

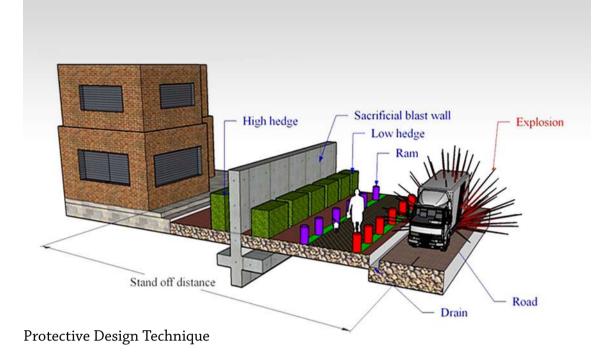
hroughout history, architecture has been used to study ancient civilisations and people's way of life. It is because of this that architecture holds great importance while planning and depicts the political, cultural and social forms.

Certain findings teach us the importance of architecture on our mental state, thought processes and how it can promote harmony.

Another aspect is the role architects, as well as structural engineers and designers play in this process and how they are one of the best suitors in promoting peace among all.

Since time immemorial, conflicts and protests have made their way in every realm of society. India, for instance, has experienced myriad insurgencies, violence, invasions and wars. The normal state of being is peace, but this 21st-century world scenario most likely would portray the opposite. In this case, it becomes vital for architects to ask the question, "Can architecture be peaceful in a conflict zone?" Japanese architect and Pritzker Prize winner Tadao Ando said, "The way people live can be directed a little by architecture." Hence, it is evident that the two cannot be separated and there must exist a cohesive bond to strengthen this relation. India, with its unity and diversity, is beset with socioreligious, economic, cultural and sectarian challenges. Its silent architectural protest must be one on a more profound scale.

Most architects only regard peace as a favourable condition for architecture, not as a condition which itself can be designed. A great deal of reconstruction takes place in the aftermath of war. Can this be done in such a way that it creates more peaceful relations among inhabitants in the future? Is an 'architecture of peace' possible? This was the central question at a conference of architects and social scientists at the Netherlands Architecture Institute in May, 2010.



Certain findings teach Us the importance of architecture on our mental state, thought processes and how it can promote harmony. Another aspect is the role architects, as well as structural engineers and designers play in this process and how they are one of the best suitors in promoting peace among all.

According to Prof. Gerd Junne, an academic entrepreneur, architects have specific competencies. They could be playing a more meaningful role in the following areas:

- Architecture is about the organisation of space. Architects can assist by designing spatial arrangements that are more conducive to stability and peace.
- 2. Architects focus on the future. They build for future use. Conflicting parties are often prisoners of their past. They blame each other for past atrocities. Architects can turn their attention from what has been to what should be.
- 3. Architects are trained to provide for human needs.
- 4. Architects work in an interdisciplinary way.
- 5. Architects have a natural sense of sequence: the second floor cannot be built before the first. This ability can also help to formulate post conflict development strategies.
- 6. Architects are used to complexity and trained to understand the interaction between a building's different components.

7. Architects want to build something solid and lasting. They aim at stability, which is highly desirable in a post-conflict situation.

Architecture cannot be considered a standalone entity. It is an evident part of the landscape and environment around it. It has a strong psychological and emotional influence on the minds of those who enter and experience it.

Renowned architect Charles Correa said, "You cannot look at cities without wandering into the architecture on the one hand and politics on the other." Unfortunately, since the last few years, real estate has become the primary source of financing political parties. The question, therefore, that should arise among architects is, 'Are we practising our profession morally and ethically?' Our land is too precious to be squandered in this manner because ultimately, today's actions will determine tomorrow's future.'

Space utilised to its optimum level can become an important aspect of growth. People's will to survive brings them towards cities but can cities handle the rising number of people in it?

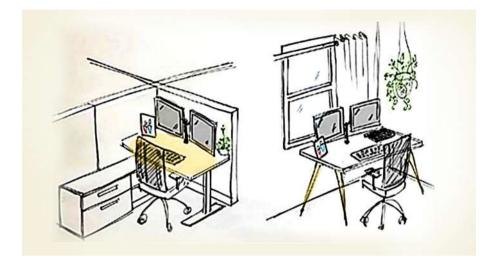
Tadao Ando said, "We borrow from nature, the space that we build upon." All infrastructure that we build has a lasting effect on the environment. To acquire land to build, various natural habitats of flora and fauna are destroyed and people are displaced. How can one reduce this impact and avoid it in some cases? Sustainability and green architecture have thus succeeded in providing some light at the end of the tunnel.

It is the mission of environmental psychology to show how our spaces, buildings, cities and landscapes make us feel and behave. Dave Alan Kopec, a professor at the New School of Architecture and Design in San Diego, defines it as "the study of human relations and behaviours within the context of the built and natural environments."

When we think of a building in its most fundamental way, we notice it as a means of creating an inner space to protect us from outside threats. Therefore, architecture has evolved to be a means to provide shelter for its inhabitants especially where conflicts arise and the idea of living in groups was brought into the picture.



Environmental psychology overlaps with many other established design disciplines, including space planning, ergonomics, lighting, acoustics, way-finding, branding, and interior design. Its methods and



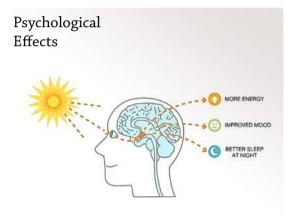
conclusions are astonishingly precise. For example, research has proved that locating a sink within the visible stretch of a hospital corridor can increase the rate of handwashing and that installing operable windows in a school classroom can reduce sleepiness.

It remains the architect's responsibility to integrate input from environmental psychologists into a compelling holistic structure.

When we think of a building in its most fundamental way, we notice it as a means of creating an inner space to protect us from outside threats. Therefore, architecture has evolved to be a means to provide shelter for its inhabitants especially where conflicts arise and the idea of living in groups was brought into the picture.

The urban design thus emerged as a method to view the built environment as a means to unite cohesively rather than treating each building as a singular entity. With this, cities emerged as places having a conducive ecosystem of not only providing shelter but also as a place for social interaction and a healthy balanced economy.

A relatively new form of architectural design is 'Protective Design'. This type of design is believed to save lives to a far



greater extent especially when violence and conflict strikes. This method will protect inhabitants through its façade design. This is called 'peace-sensitive architecture'.

There are many more methodologies through which a 'Peace Sensitive Architectural Approach' can be implemented. It must be studied in-depth and included in the academic curriculum of architectural and construction schools. If students are exposed to such concepts at the very start, it will shape the mind to think sensitively. This will play a great role for the future as it would enhance the quality of life as well as protect the natural environment from being destroyed.



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UDBODH Doing Their Bit for Dementia Care

The provide accurate data for various reasons. Therefore, community-based organisations and educational institutions have a big role to play in building systematic care for people with dementia.

One of them is Udbodh. It is the third initiative of the Prajna -- Centre for Neuroscience, Cochin University of Science and Technology, in association with the district administration. As the title Udbodh means, 'to awaken or enlighten,' the project aims to encourage society to have compassion towards people with dementia and thereby help in building a comprehensive care system.





Udbodh has developed intervention systems in the community, such as a Memory Café, Memory Clinic, Memory Screening, Awareness programmes, and Care centres. Also, Udbodh has developed a mobile-based app for connecting care systems to help facilitate dementia care. This is known as the Dementia Friendly Community (DFC). Udbodh had selected Cochin Corporation to build a model DFC. The Corporation has accomplished the goal. Today, Kochi is the first dementia-friendly city in India.

Activities of Udbodh

a) To bring a perspective on dementia research and care, an international conference on Alzheimer's in science and society was organised at Cochin University of Science and Technology on November 1-3, 2019. It was not just an academic conference; instead, it was a comprehensive approach to building a dementia-friendly community.

Academic discourses, new perspectives in care, and changing trends in research and community programmes were presented. Those who took part included representatives from law enforcement, the state's social justice and health departments, college students, school teachers, senior citizens clubs, resident associations, and members of the panchayat, municipality, and corporation, accredited social health activists, and Anganwadi workers. b) On September 21, 2019, a Memory Walk was organised at Kochi. Around 1600 people took part. This is regarded as the biggest memory walk in Asia. People from various sections participated. The aim was to enable civil society to address dementia issues and generate maximum social security. It is time for students, the Indian Navy, advocates, and the police to provide support to people with dementia.

c) Awareness programmes have been organised in schools, colleges, senior citizen forums, resident associations, among accredited social health activists, Anganwadi workers, and police in the premises of the corporation.

d) Theatre performance is one of the best methods to bring public attention. So, taking Alzheimer's disease as the theme, the project organised a street-based theatre in Kochi. A flash mob was also organised.

e) Public awareness through kiosks: A kiosk with information about Alzheimer's disease was conducted at select places. The public was encouraged to share their concerns and doubts related to dementia. In addition, the kiosk had free-of-cost memory screenings.

f) There were awareness classes for panchayat members, counsellors and municipal workers The panchayats are India's basic unit of governance. In Kochi, there are 82 panchayats, 14 municipalities, and one corporation. Creating awareness among the panchayat members will help develop dementia-friendly projects at the local level. People of lower socio-economic status may get assistance in future.

g) Orientation classes are also important when considering dementia as a health care priority. Many hospitals and health care professionals do not know how to handle patients with Alzheimer's disease when a case is presented to them with a dissimilar health condition. The programme is aimed to improve the knowledge of healthcare professionals. The classes were organised in association with the Indian Medical Association. Experts took classes at major hospitals and nursing colleges.

h) Memory café refers to a socialisation process that aims to convene all the members who either have lost their social life or compromised their careers due to the occurrence of Alzheimer's disease. It aims to eradicate the stigma of the disease. The café is a place where people can interact, laugh, cry, find emotional support, share concerns and celebrate without feeling embarrassed or misunderstood.

The café encourages friendship and acceptance. This is not a one-time event. Instead, it is the first step to build a stigmafree city where family members or informal caregivers will gather periodically and advocate for a dementia-friendly society. Since it is marked as the first café in Kerala, it may bring wider media and public attention. It will also encourage society to have a similar system in their areas.

On October 20, 2019, Kerala's first memory café was organised at Tonico Café, Kakkanad, in Kochi.

i) Once a person is identified with dementia, they, as well as the family, have to be further supported with clinical care and counselling. Hence, the Dementia Care Plan Clinic is an essential component. The clinics will run diagnostic tests to confirm dementia, initiate treatment, and provide counselling to the affected.

A clinic comprises social workers, geriatricians, psychiatrists, and neurologists. Udbodh has established a clinic at Lourdes Hospital in Kochi. Another one was inaugurated at the General Hospital on October 16, 2021.

j) Suppose a person with dementia prefers a social living environment that may offer a more professional approach, then a respite care setting may be the ideal option. It is well-known that people at home may become exhausted due to care burdens, and the informal caregiver needs a break.

Thus, respite care provides caregivers with a temporary rest from caregiving while the person with Alzheimer's disease continues to receive care in a safe environment. It supports and strengthens your ability to be a caregiver.



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The respite care may offer you a chance to spend time with other friends and family or relax. It also provides comfort and peace of mind knowing that the person with dementia is spending time with another caring individual. People with dementia may be provided with a chance to be social and to participate in staffed activities such as music and exercise programmes.

Services at dementia respite care centre

- The centre provides support services for people with dementia and their families.
- A person with dementia requires medical services like insulin shots, and help with medication. The centre will provide the necessary assistance.
- The centre will provide nutritious meals and snacks. It will conduct nutrition education programmes.
- The centre will provide help with hairstyling, toileting, eating, showering, and other tasks.

 Daily activities may include music, art, recreation, discussion and support groups, behaviour modification, and other therapies.

There is a mobile app for care services at Cochin Corporation. Through the app, you can avail of counselling, care services, clinics, and dementia-friendly care providers.

Unique Efforts

Udbodh is the first dementia care project for panchayats in India. This project has achieved yet another milestone. The Koovappady Block Panchayat in Ernakulam District has adopted the project guidelines and incorporated dementia care as a priority in its year plan. The inauguration of the project, titled 'Smrithiparvam' by MLA Eldhose Kunnappilly, took place on February 14, 2020, in the presence of Panchayat President Bindhu Gopalakrishnan. Dr. Baby Chakrapani, Director of the Centre for Neuroscience and Project Director of Udbodh provided training on the use of the mobile app for dementia diagnosis to the health care workers present at the function.

Dr. Baby Chakrapani is the Director of the Centre for Neuroscience, CUSAT and the Project Director of Udbodh. Prasad M Gopal is the Project Coordinator.

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Life without Limits Inspiration for A Ridiculously Good Life

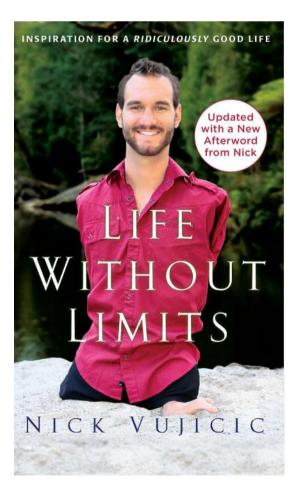
Inspiration for by Nick Vujicic

ife without Limits' is an autobiographical book by Nick Vujicic. For those who are unfamiliar, Nick, the son of Yugoslavian immigrants in Australia was born without all four limbs. Yet, he leads a life more adventurous than most people and is one of the most inspirational figures in the world today.

This book delves deep into the sources of his boundless optimism, vibrant joy and limitless energy.

What sets the book apart from other inspirational books is best expressed in his own words: "every lesson came from my own experience and they did not come easily".

Faith is the core theme. For those who practice other faiths, agnostics or atheists, this bold assertion of his faith may not be appealing. But, if we take the faith away, there is no Nick who



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inspires us. "You and I could not live without faith, without putting our trust in something for which we have no proof," he says.

Nick says that he chose to believe in the faith he was brought up in and found his life's purpose through it. In his own words, "Whatever your beliefs, you should never be without hope because everything good in life begins with it." This is the mindset recommended while reading to make Nick's experience relatable and applicable to readers of all faiths and beliefs.

'Life without Limits' is the story of how a limbless 10-year-old boy who tried to drown himself in his bathtub out of despair transformed himself into an adventure-seeker. Swimming alongside sea turtles and surfing on high waves and teaching people to lead a ridiculously good life.

Nick shares how he felt rejected when he heard that his mother refused to hold him when he was born, his frustration when he told his mom that he is sick of living with no arms and legs, the depression in his pre-teen years that led to suicide attempts, and the fears about how he would live beyond 21 years. Nick felt that to find a job, a wife and starting a family seemed impossible with the severe handicaps he had.

But he found his anchor in his faith. Despite a supportive family, Nick felt he was a mistake made by God and believed he had no purpose in life. In the book, Nick shares how he found his life's purpose through faith.

Nick has his defining moment when he meets 19-month-old Daniel - with the same condition as his. Nick didn't get the miracle he prayed for since childhood, to get limbs. When Daniel's mother cried out that he is the miracle she had been praying for, Nick realises that

This book delves deep into the sources of his boundless optimism, vibrant joy and limitless energy.

God created him the way He did with a purpose.

The book has chapters on faith, hope, sense of purpose, self-acceptance, trust, positivity, pursuing dreams, embracing the moment, and reaching out.

These are not pearls of wisdom spewed randomly but are forged by his own experience and those of others from whom he draws inspiration.

Nick does not keep the spotlight only on him. Instead, he takes a collective journey, speaking about his heroes who inspired him.

Bethany Hamilton, the surfer who lost her arm in a shark attack, but returned to surfing within weeks; Christy Brown who became a swimmer, artist, author and poet despite his cerebral palsy; Joni Eareckson Tada who became paralysed in a diving accident but went on to become an inspirational author; public speaker Reggie Dabbs who inspired Nick to become a motivational speaker. He also draws inspiration from people he meets in his visits to different countries across the world. These are people who live in impoverished conditions but choose to thrive and be joyful despite their suffering.

The solidity of the book comes from Nick's conviction that faith alone is not sufficient to find one's purpose. You need to take action and be practical. God helps those who help themselves is a core theme for Nick along with faith and hope.

It is deeply touching that Nick never considers his physical challenges the greatest or the severest in the world. He expresses gratitude for all the blessings and support he has received. The reader may be tempted to think that it's not a bad thing to be without hands and legs.

His spirit of gratitude shines the brightest when he says that despite his physical challenges, he is grateful that he has not experienced abuse or neglect which he considers to be greater suffering. Nick finds that he is much more blessed than impoverished children, women forced into sexual slavery, men imprisoned due to debts, victims of tragedies, and bedridden persons. Acknowledging that there is pain greater than his helps him to count his blessings and not what he lacks. He



 Life without Limits' is the story of how a limbless 10-year-old boy who tried to drown himself in his bathtub out of despair transformed himself into an adventure-seeker.
Swimming alongside sea turtles and surfing on high waves and teaching people to lead a ridiculously good life.

does not see the world through the prism of his suffering.

Nick expresses a profound sense of community by connecting with people. The empathetic hug he received from a child who folded her hands behind to resemble him while hugging. Nick cried when he saw the malnourished orphan boy in Cambodia who waited for hours to see him. The understanding he shows towards those who have difficulty relating with him for the first time is another instance of his empathy.

Nick's humour is another takeaway. The biggest surprise would be the head butt fight he had with a classmate who dared him to fight - literally drawing blood from his opponent.

His burning desire to reach out, to give, to find his purpose by living for others is the driving force of his life and with faith, he is inspiring millions of people in the process.

The reviewer is a Freelance Social Worker in Patna, Bihar.



D^{ear Editor,} Very thoughtful editorial and many insights into the fundamental principle that all religions seek peace.

However, in a real life real time, you have the rather sorry spectacle of the Roman Catholic Bishop of Pala making accusations of narcotics jihad and love jihad against another religious group. How such statements are conducive to peace and communal goodwill is a matter to be considered most seriously by his higher ups. Also, if there is complete silence, what does it signify?

Jagan Mathews

Kochi

D_____

The issue of PAX LUMINA on Religion and Peace effectively brings forth how depraved the organized religion can become divorced from spirituality. Often in unholy alliances with politics and driven by the urge for conquest of wealth and power, religion becomes cause for violence of various types and marginalisation in societies. The happenings in societies and countries narrated in this issue give ample evidence of this. The failure of religion to inculcate the knowledge of the Holy and of one of the main purposes of religion, viz. to serve God and man in its followers often leads to making of societies marked either by fanaticism or paralysis of action. In contrast, the article MAKING PEACE WITH FAITH by Garred and Abu-Nimer drives home the feasibility of potential for imparting new insights to faithbased peace building and establishing a new world order ensuring sustainable peace. This is extremely encouraging and refreshing !

Truly, **K A Joseph** Kochi

D^{ear Editor,}

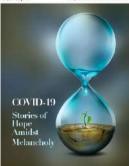
Thanks for Pax Lumina September 2021 edition and the main focus is on 'Religion and Peace'. Human beings need knowledge, skills, values and principles. Science will provide knowledge and skills and religion will help us to emulate values and principles. In the fast growing world of science and technology, a harmonious blending of scientific ideas and religious values/ethical principles, is not an option but an obligation for the humanity to progress along the right path. Albert Einstein pointed out that science without religion is lame, religion without science is blind. This statement reflects the mutual interdependence of science and religion. Scientific discoveries are accountable when it is carried out responsibly, stewarding nature and ensuring peace, harmony and order in the world. In order to establish peace in the society, the amalgamation of ethical and religious values/principles with the scientific ideas is inevitable.

Dr. (Sr) Beena Jose Thrissur

Dedicating an entire edition to the current developments in Afghanistan by itself speaks volumes about the gravity of the situation. All the articles are very well written. The different perspectives by each author has only scratched the surface of the mammoth sized issue. Congratulations again on the splendid work!

Shruthi H Trivandrum

Pax Lumina





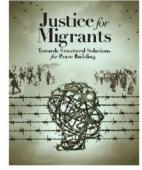


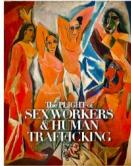
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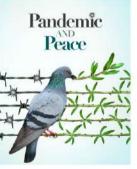


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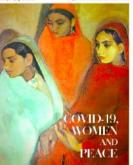




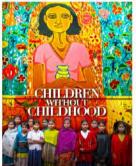
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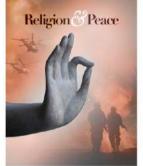
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