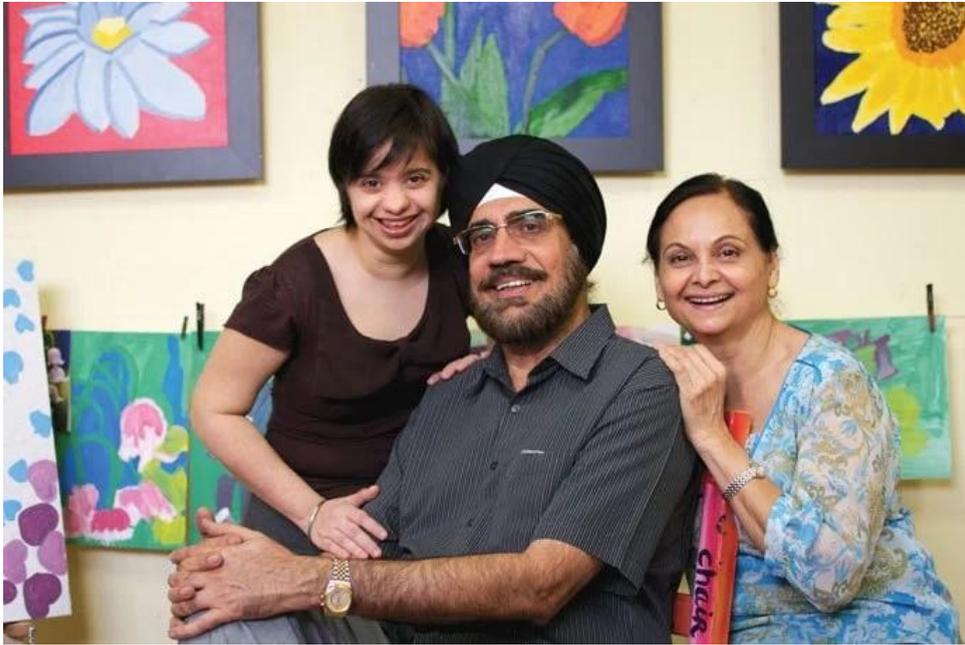


Balbir Singh: Advocating support for people with Down Syndrome

What started as a personal matter some 30 years ago for BALBIR SINGH has become his mission to put the issue of Down Syndrome on the national and international agendas. He overcame adversity and succeeded. He is a disability advocate and with many like him at the forefront of this movement, more positive changes are bound to happen over the next 50 years.

By **Asia Samachar** - April 11, 2016



Balbir Singh with his wife and daughter Jaspreet Kaur Sekhon (left) seen in a photo published in 2014 at IndiaSE, a magazine for global Indians.

The two most distressing words from an obstetrician to parents of a new-born child would possibly be 'Down Syndrome', coloured with the bleakest of information about the condition. Even after years of research, advances in treatment options and improvements to public education, Down Syndrome remains one of those chromosomal accidents of genetics that continues to occur in about 0.1 per cent of the population. Singapore has come a long way in recognising and treating this condition, due in large part to the work of Dr Balbir Singh, his family and peers.

Balbir has devoted much of the past 33 years advocating for a better quality of life for the intellectually challenged, particularly people with Down Syndrome. In 1980, his daughter, Jaspreet Kaur, was born with Down Syndrome. Although his wife, Rabinder Kaur, their younger daughter, Parveen Kaur, and him consider themselves lucky to

have had the full support and understanding of their extended families right from the time of Jaspreet's birth, they faced many challenges at a time when not many resources were available in Singapore on finding strategies and information for bringing up a child with an intellectual disability, in an environment where damaging myths and misconceptions about the condition abounded. This propelled Balbir to educate himself and gather resources by attending conferences abroad, where he was able to meet educators, researchers, therapists and clinicians, many of whom would later help him enrich the lives of Singaporeans living with intellectual disabilities beyond the personal sphere of his immediate family.

Balbir went to medical school in Amritsar, in India, as an Indian government nominee, and has worked as a corporate physician at the aviation gateway services and food solutions provider, Singapore Airport Terminal Services, for decades. He credits the travel benefits of his job for having allowed him the leeway to make valuable overseas contacts who have greatly aided his work.

Balbir joined a parents' group at the Singapore Association for Retarded Children (SARC) [now known as the Movement for the Intellectually Disabled of Singapore] when Jaspreet was growing up and started a new support group called Helping Our Parents Emerge. These groups served as a valuable starting point from which parents and caregivers of children with intellectual disabilities could come together for not just support, but also to begin serving as lobby groups to convince Singapore society that better services and programmes were needed for persons with Down Syndrome and other intellectual disabilities.

Balbir eventually became an executive committee member of SARC and played a key role in helping SARC launch the 'Early Intervention Programme for Infants and Young Children' in 1990, which was later taken over by the National Council for Social Service (NCSS) and developed into the Rainbow Centre of today. Balbir was also the founding Chairperson of Down Syndrome Association, established in 1995 with the guidance of one of his overseas contacts – Mrs Penny Robertson, President of the Australian Down Syndrome Society at that time.

Some of the initiatives Balbir has lobbied and advocated for, and achieved include the formation of a national social service agency dedicated to enabling persons with disabilities called SG Enable, the implementation of special education training courses for teachers and the setting up of the Special Needs Trust Company. His efforts at getting recognition for people with intellectual disabilities at the national level have resulted in Singapore now being a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Among his greatest accomplishments is the introduction of the World Down Syndrome Day, which he and other international disability advocates had been proposing since 2005, and which was ratified at a United Nations (UN) conference in 2011. World Down Syndrome Day is now marked on 21 March every year.

This has really made a difference in other countries. For instance in Myanmar, it has really helped disability advocates there in gaining recognition and resources from the government. – Balbir Singh

On 21 March 2014, Balbir represented Down Syndrome International and as a champion of the UNCRPD at the UN on World Down Syndrome Day and made a presentation on 'Health and Well-being of Persons with Down Syndrome'. It was a milestone event, with support from such organisations as the UN and the World Health Organization.

As a third generation Singaporean Sikh hailing from a family of cattle traders, Balbir draws much inspiration from his family which has been involved in the community and ingrained in him a certain kind of stubbornness or refusal to be held back by a few minor failures. One of the biggest challenges he faced in the early advocacy years was hearing a constant stream of "no" answers from the government every time it was approached for assistance, funding or suggestions on disability-related programmes. Despite initial resistance, Balbir's commitment to empiricism, his willingness to share and preparedness to sometimes be laughed at and yet persevere was what helped eventually change the government's thinking and approach towards the disability sector.

The government is not the only entity that has required a mindset change. When asked about the stereotyping people with Down Syndrome face, Balbir was candid about the fact that, culturally, Singapore's society continues to hold negative views. He remembers making a conscious effort to bring Jaspreet out with the family when she was a child as he believes exposure outside the home contributes significantly to development but recalls that Jaspreet and others like her often bear the brunt of stares and gaping on the streets.

However, Balbir was more taken aback by negative reactions from the medical community. He remembers hearing a lot of negativity and 'doom and gloom' messages from medical practitioners in the past about caring for children with Down Syndrome. He believes the medical community has come a long way in its receptiveness to new treatment options, especially with the increasing focus on early intervention.

Balbir is passionate in advocating a better life for persons with disabilities. This is evidenced in his dedication and contribution as President of Down Syndrome Association and with MSF. Since 2012, Balbir has been a member of the Enabling Masterplan Implementation Committee 2012-16, which was set up by MSF to monitor the progress of the recommendations of the Masterplan. He provided good ideas such as the use of technology in early intervention and the need to improve support for parents and caregivers through better access to information and training. He also co-chairs a workgroup with MSF on improving healthcare access for persons with disabilities.

Balbir helped steer the work group with fresh perspectives and initiated a course on improving the awareness of healthcare for persons with disabilities with the College of Family Physicians Singapore.

Balbir is a keen supporter of the United Nations Convention on the Rights of Persons with Disabilities which Singapore ratified in 2013. He has been an active advocate for persons with Down Syndrome for around 25 years. He has helped to make a difference both locally and internationally through his leadership and foresight.

- Ms Wong Kuan Ying Director, Disability Division Ministry of Social and Family Development, Singapore

In 2009, Balbir received the Pingkat Bakti Masyarakat (Public Service Medal) from the President of Singapore in recognition of his service in the disability field and social service sector. In 2011, United Kingdom-based charity Down Syndrome International awarded Balbir the President's Special Recognition Award in recognition of his lifetime contributions in strengthening and enriching the lives of people with Down Syndrome. This year, Balbir was presented with the Ministry of Social and Family Development (MSF) Volunteer Award (Friend of MSF) for his valued contributions to the disability sector. He is a past President and existing Board member of Down Syndrome International. He has also served as a Board member of NCSS.



Balbir Singh – PHOTO / Singapore At 50: Sikhs and Their Contributors

Balbir often quips that with Singapore's propensity for constantly wanting to be on the top of 'best of' lists and a 'hub' for lots of things, it is surely reasonable for it to also be a top player in the disability sector. Although many challenges remain, such as funding and lengthy waiting lists for accessing early intervention programmes, Balbir feels that these are being addressed and is thankful that outcomes are now measurable in the sector. In addition, he acknowledges that labelling and stereotyping do still exist but he is hopeful that there will be much more space for that to be overcome in the future.

For Balbir, it started as a personal matter some 30 years ago but he has made it his mission to put the issue of Down Syndrome on the national and international agendas. He overcame adversity and succeeded. With disability advocates like him at the forefront of this movement, we are bound to see more positive changes in this area over the next 50 years.

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