

# DISABILITY IS THIS ABILITY

**a step-by-step guide for parents  
of children with special needs**

First of  
its kind  
book in  
India!

**DR SANJAY PARVA**

Himalaya Publishing House

ISO 9001:2015 CERTIFIED

# **Disability Is *This Ability***

*A Step-by-Step Guide for Parents  
of Children with Special Needs*

Dr Sanjay Parva



**Himalaya Publishing House**

ISO 9001:2015 CERTIFIED

© **AUTHOR**

No part of this publication shall be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording and/or otherwise without the prior written permission of the author and the publisher.

## **FIRST EDITION : 2019**

- 
- 
- Published by** : Mrs. Meena Pandey for **Himalaya Publishing House Pvt. Ltd.**,  
“Ramdoot”, Dr. Bhalerao Marg, Girgaon, Mumbai - 400 004.  
**Phones:** 022-23860170, 23863863; **Fax:** 022-23877178  
**E-mail:** himpub@bharatmail.co.in **Website:** www.himpub.com
- Branch Offices** :
- New Delhi** : “Pooja Apartments”, 4-B, Murari Lal Street, Ansari Road, Darya Ganj,  
New Delhi - 110 002. Phones: 011-23270392, 23278631;  
Fax: 011-23256286
- Nagpur** : Kundanlal Chandak Industrial Estate, Ghat Road, Nagpur - 440 018.  
Phones: 0712-2738731, 3296733; Telefax: 0712-2721216
- Bengaluru** : Plot No. 91-33, 2nd Main Road, Seshadripuram, Behind Nataraja Theatre,  
Bengaluru - 560 020. Phone: 080-41138821;  
Mobile: 09379847017, 09379847005
- Hyderabad** : No. 3-4-184, Lingampally, Besides Raghavendra Swamy Matham,  
Kachiguda, Hyderabad - 500 027. Phone: 040-27560041, 27550139
- Chennai** : New No. 48/2, Old No. 28/2, Ground Floor, Sarangapani Street, T. Nagar,  
Chennai - 600 012. Mobile: 09380460419
- Pune** : “Laksha” Apartment, First Floor, No. 527, Mehunpura, Shaniwarpath  
(Near Prabhat Theatre), Pune - 411 030.  
Phones: 020-24496323, 24496333; Mobile: 09370579333
- Lucknow** : House No. 731, Shekhupura Colony, Near B.D. Convent School, Aliganj,  
Lucknow - 226 022. Phone: 0522-4012353; Mobile: 09307501549
- Ahmedabad** : 114, “SHAIL”, 1st Floor, Opp. Madhu Sudan House, C.G. Road, Navrang  
Pura, Ahmedabad - 380 009. Phone: 079-26560126;  
Mobile: 09377088847
- Ernakulam** : 39/176 (New No. 60/251), 1st Floor, Karikkamuri Road, Ernakulam,  
Kochi - 682 011. Phones: 0484-2378012, 2378016; Mobile: 09387122121
- Cuttack** : New LIC Colony, Behind Kamala Mandap, Badambadi,  
Cuttack - 753 012, Odisha. Mobile: 09338746007
- Kolkata** : 108/4, Beliaghata Main Road, Near ID Hospital, Opp. SBI Bank,  
Kolkata - 700 010. Phone: 033-32449649; Mobile: 07439040301
- Cover Picture** : Dr Sanjay Parva
- Cover Design** : K Sayyed
- DTP by** : Sudhakar Shetty
- Printed at** : SAP Print Solutions Pvt. Ltd., Mumbai. On behalf of HPH.

## *for you all*

*Wouldn't have written this,  
But for you, Badshah, my son  
Thank destiny for it, and you,  
One, just one – and only one.*

*And for you, Princess,  
The promised fiction, upon I'll swoon  
Get you the long-awaited doonikul\*,  
I swear – very, very soon.*

*On arduous life, weak and weary,  
When no song we ever heard  
Your hope and faith, Bulbul,  
Thankfully is – what I heard.*

\*Doonikul: Kashmiri name for a walnut tree



# PREFACE

---

This is the first book of its kind in India, which sets a direct tone with parents of children with special needs and guides them such that can relieve them of their anxiety.

It is a long story about why I wrote this book. But that would need another book to tell. If I am destined to, I would. If I don't, let's hope someone else would eventually write one on a similar story. By someone, I assume a parent of a child with special needs. They only know what it means to raise a child with special needs, and at times, how difficult and desperate it can get.

Particularly in a country that has no appropriate mechanism to guide such parents away from fear and anxiety; so compounded by each passing day that more often than not the domestic clutter that follows begins to take its toll on almost everything else – their personal life and health, their social life, their sense of security; both for them and their child, attention towards the second child, personal and family mobility, and participation in family or community oriented gatherings. Then, as if it was not enough, there are these volley of questions from a society which is grossly ill-informed about problems faced by this population group.

This is just the tip of the iceberg. You only need to be the parent of a special child or a well-wisher of such a parent to understand the anguish and pain. The pain is immense, and if not handled well, it can turn into a ticking time bomb of grief, sinking both parents into an abysmal state of emotional upheaval. This, in no case, should happen – as you are not alone.

Out there in this small world, there are 93 million plus children who have special needs. But, they have special parents, too. Special because destiny very well knows the resilience of a parent in whose lap such a child it brings. Affirmative attitude and patience are the keys to bringing up and caring for such children. If you as a parent wouldn't, who would? You have a greater responsibility to shoulder than an average parent.

I started meeting such parents in 2009. Most of them were initially reluctant to speak; many whom I meet now, are still – a scenario that must change. If

such parents don't speak to each other or with parents who do not have children with special needs, how can the latter be informed about the needs of such children, and even the needs of such parents.

In an inclusive society, everyone must know; because keeping children with special needs in isolation is further damaging their physical and mental health. Never do it.

Issues related to such children need to be discussed openly; both among their parents and society at large to find ways and means of providing them with better and effective care while sensitising the society about its responsibility towards children with special needs.

During the course of my interactions with these parents, many startling observations emerged. The most disturbing one was that right from the birth of the child, with or without a diagnosis, parents ran from pillar to post in search of the right guidance.

Most of the parents, as they revealed, ended up being clueless about almost everything – the medical specialists to consult for an accurate diagnosis, the school they must consider or which would take in the child, the type of education that must be imparted to the child, and the type of education which he would actually be receptive to, role of clinical psychologists, parents' own responsibility, their rights, and general dos and don'ts.

Problems these parents faced outnumbered solutions in hand. And there was no let up in their day-to-day anxiety. Anxiety was palpable when I would track parents and come to know that they were changing schools of their children quite too often. The reason is that no sooner did they admit their child in a particular school than did they realise they had made the wrong choice. Too many wrongs in succession in a year, while the child grew, compounded their worry further. That was another aspect to probe.

In one instance, I came in touch with a speech therapist, who had in her school children from almost all impairments, charging hefty money in cash from hapless parents. No parent questioned her or asked for her degrees, approvals to run the school in her gully, not to speak of confronting her with a query or concern regarding any child. If at all someone dared to ask, her replies would be vague and unscientific.

Then, there were this motley group of teachers, trained or not in special education, who came together, established yet another 'shop', created artificial scarcity of 'seats' in their two-room school, and then finally admitted one and all. To make the set-up appear out of this world, and the best in the town, they had pegged their fee slabs higher than the ones parents were previously distraught with. For a parent, it was like falling willingly in a vicious circle and trying to finding some panacea in what was otherwise an inexorably painful cascade of a fresh set of negative events.

Most of the parents didn't even know about some not-for-profit organisations running different types of school for children with special needs and doing genuine work, so as to make an informed decision right from the start.

Parents didn't even know about the laws that existed in their favour and the ones which they could use to fight for their cause and concern. This book has included all four laws as annexures at the end for parents to go through and understand the rights which they have as parents of children with special needs.

In all, I could conclude that each parent resented having lost precious time in being clueless. I realised there existed a huge information gap, which required to be bridged – one reason why you are reading this book now.

While the Government of India has taken certain proactive decisions with regard to children with special needs in recent years, there is a lot which parents are also supposed to do and accomplish. Parents need to form a support group, which can take up their issues with the government bodies, media, and other groups, within and outside the country, for better reach and impact.

If you are a parent, a support group, a special school, a not-for-profit organisation, or even a common man with a noble cause, and you feel you, I and many more can team up for the cause, I would love to hear from you.

*Vasudhaiva Kutumbakam.*

**DR SANJAY PARVA**  
([iknowparva@gmail.com](mailto:iknowparva@gmail.com))  
New Delhi, June 28, 2019



# CONTENTS

---

Chapter 1 :	They Discovered Their Ability in Their Disability	1 – 4
Chapter 2 :	What is a Disability?	5 – 24
Chapter 3 :	Understanding the Developmental Changes of Your Child	25 – 29
Chapter 4 :	Types of Disabilities	30 – 43
Chapter 5 :	How Much Should You Worry or Should You Worry at All?	44 – 52
Chapter 6 :	How to Boost Your Child’s Confidence and Self-esteem?	53 – 62
Chapter 7 :	Choosing the Right Toys and Indoor/Outdoor Activities	63 – 68
Chapter 8 :	Common Barriers of Disability	69 – 85
Chapter 9 :	Can Your Child Go to School?	86 – 112
Chapter 10:	Resources that You Can Use	113 – 137
<b>ANNEXURES</b>		
<b>Annexure 1:</b>	The Rights of Persons with Disabilities Act, 2016	141 – 203
<b>Annexure 2:</b>	The Right of Children to Free and Compulsory Education Act, 2009	204 – 225
<b>Annexure 3:</b>	The National Trust Act, 1999	226 – 277
<b>Annexure 4:</b>	United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol	278 – 313

# DETAILED CONTENTS

---

<b>Chapter 1: They Discovered Their Ability in Their Disability</b>	<b>1 – 4</b>
Stephen Hawking	
Tom Cruise	
Albert Einstein	
Thomas Elva Edison	
<b>Chapter 2: What is a Disability?</b>	<b>5 – 24</b>
Difference between Impairment, Disability, and Handicap	
Why Only Your Child and Why Only You?	
You are Not Alone	
Disabled World	
A Snapshot of Global Disability Statistics	
Disabled India	
Disabled Population in India – Census 2011	
Disabled Society	
Dismal Social Acceptance	
Factors Influencing the Incidence of Disability	
Genetic	
Environmental	
<b>Chapter 3: Understanding the Developmental Changes of Your Child</b>	<b>25 – 29</b>
Birth to 3 months	
4-6 months	
7-12 months	
1-2 years	
2-3 years	
3-5 years	
5-8 years	

Understanding Developmental Delays in Your Child

The Link between Developmental Delays and Disability

**Chapter 4: Types of Disabilities** **30 – 43**

Impairments

Developmental Disabilities

Intellectual Disability

Cerebral Palsy

Autism

Epilepsy

Physical Disabilities

Speech and Language Disability

Learning Disabilities

Auditory Processing Disorder

Dyscalculia

Dysgraphia

Dyslexia

Language Processing Disorder/Dysphasia

Non-verbal Learning Disabilities

Visual Motor Deficit/Visual Processing Disorder

Attention Deficit Hyperactivity Disorder (ADHD)

Mental Health Disabilities

Emotional Disturbance

Traumatic Brain Injury

**Chapter 5: How Much Should You Worry or Should You Worry at All?** **44 – 52**

What Does All This Mean to You?

At Home

Outside Home

At School

How to Deal with Hurting and Teasing Behaviour of Others?

How to Handle Hurting or Negative Reactions to Disability?

<b>Chapter 6: How to Boost Your Child’s Confidence and Self-esteem?</b>	<b>53 – 62</b>
Improving Your Own Confidence and Self-esteem	
How to Promote Sibling Association?	
How to Deal with Such Feelings?	
<b>Chapter 7: Choosing the Right Toys and Indoor/Outdoor Activities</b>	<b>63 – 68</b>
Matching Toys with the Disability	
<b>Chapter 8: Common Barriers of Disability</b>	<b>69 – 85</b>
What is a Barrier? Why do we Need to Talk about Barriers	
Attitudinal Barriers	
Communication Barriers	
Physical Barriers	
Policy Barriers	
Programmatic Barriers	
Social Barriers	
Transportation Barriers	
A Flicker of Hope through Disability Laws in India	
Persons with Disabilities (PWD) Act, 1995	
Provisions of the Act	
The Rights of Persons with Disabilities Act, 2016	
What are Your Rights?	
Rights that You Know	
Rights that You Don’t Know	
Rights that You Don’t Execute	
Rights that You Must Have	
<b>Chapter 9: Can Your Child Go to School?</b>	<b>86 – 112</b>
Formal or Regular Schools	
Special Schools	
National Open School/National Institute of Open Schooling (NIOS)	
The Need to Consult a Clinical Psychologist	
What are Special Schools and What is Special Education?	

Why Does Your Child Need a Special School?  
 How to Know that Your Child has Special  
 Education Needs?  
 How to Choose the Right School for Your Child?  
 What Role do You Play in the Special Education  
 of Your Child?  
 What is Individualised Education Program (IEP)?  
 Only School is Not Enough, Think of  
 Homeschooling Too  
 Home Provides an Ideal Environment for Your  
 Child's Education  
 Play an Active Role in Your Child's Education  
 How to Determine the Learning Style of Your  
 Child?  
 Teaching Strategies for You Based on Your Child's  
 Disability  
 A Small World of Your Own: If it Doesn't Exist,  
 Create it  
 Create a Community of Your Own  
 Finding an Existing Group  
 Starting Your Own Support Group

**Chapter 10 : Resources That You Can Use 113 – 137**

Organisations Working in the Field of Disability  
 The National Trust  
 Department of Empowerment of Persons with  
 Disabilities  
 Legal Rights and Acts

**ANNEXURES**

<b>Annexure 1:</b>	The Rights of Persons with Disabilities Act, 2016	141 – 203
<b>Annexure 2:</b>	The Right of Children to Free and Compulsory Education Act, 2009	204 – 225
<b>Annexure 3:</b>	The National Trust Act, 1999	226 – 277
<b>Annexure 4:</b>	United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol	278 – 313





CHAPTER

They  
Discovered  
Their Ability  
in Their  
Disability

Only the wearer knows where the shoe pinches. If you are the parent of a child with a disability; only you know what it means to be one, and how it feels. But, you are not alone. You are a parent of one of those 93 million plus children in the world who have some or other form of disability. These children, and also their parents live with their disabilities every single hour of the day. And they are moving on — some bravely, some weakly and some have even discovered new life and meanings in their disabilities. The latter includes many who have made a difference in this world irrespective of their disabilities. For the sake of infusing hope in you, this book would like you to meet some. Here we go.

## ❖ **Stephen Hawking**

What would you do if the doctors gave you just two years to live?

Sulk in silence! All the dreams and aspirations will crumble in a wink. The clock ticking on the wall would seem like an internal alarm hijacking your mind and leaving you helpless waiting for your end.

This would have been his destiny too if he hadn't been inspired by a child suffering from cancer. "My condition is far better than him," the renowned scientist Stephen Hawking had once told himself.

Hawking chose to overcome his disability rather than be a slave to it. In fact, he defeated his disability and kept moving. Despite his disability, he was destined to contribute to the scientific world in the major way that he did.

He was diagnosed with a neurological disease at a young age of 21 years that left him paralysed and bound to a wheelchair for his entire life. As if that was not enough, he needed a speech synthesiser to communicate what he intended to speak, but couldn't.

Hawking didn't make his disability come in his way of success and today and in future, the world would remember him as a great physicist.

At one point his remark on disability was this: "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."

## ❖ **Tom Cruise**

Below average height, not particularly handsome and described as a 'functionally illiterate' person, this Hollywood actor from America is now a heartthrob of every movie buff. But, at one point no one would have expected him to deliver his lines as flawlessly as in *Top Gun* or *Mission Impossible*.

Winner of three Golden Globe Awards, he was diagnosed with dyslexia at the age of seven and struggled with reading at his school and even in his earliest roles as an actor.

Most of the time during his childhood, he would hide his disability from others, fearing being ridiculed. But, as it goes, “everything is easy when you are crazy.” Tom was crazy about acting despite his dyslexia; which though being an obstacle failed to work as one.

Tom accepted his disability and joined a programme to overcome his reading and learning problems. He refused to let dyslexia stand in his way of a successful career. And here he is.

### ❖ **Albert Einstein**

Best known for his theory of relativity which forms one of the pillars of modern physics, Albert Einstein is worshipped as god by the modern scientists and physicists.

People view him as a person with some extraordinary skills and above average intelligence. But, rarely does anyone know that he had a learning disability and could not speak until the age of three years. He was labelled as dull, dyslexic, and even autistic. Isn't that difficult to believe? It is. But it is true.

Einstein never paid heed to his learning disability; rather focused on his interest in physics and inquisitiveness to learn.

And today this dyslexic personality has given valuable contributions to the field of science.

### ❖ **Thomas Alva Edison**

“To invent, you need a good imagination and a pile of junk.” These are the words of the greatest American inventor, Thomas Alva Edison. He was a prolific inventor holding more than 1,000 patents in his name.

He is mostly known as an inventor of the electric bulb. But, he also invented a phonograph and the motion picture camera.

‘Brilliant’ and ‘genius’ are the words anyone would rhyme with Edison. “Must have been a man with a sharp mind,” you may say.

But, this sharpness of mind was not reflected in his early years. He was diagnosed with a learning disability and could not read until the age of 12 years.

Recurrent untreated ear infections in childhood and a hard blow by the train conductor caused him to lose his sense of hearing at an early age.

However, this could not dampen his spirits. Indeed, they were considered as an asset by Edison that allowed him to concentrate on his experiments and research.

Edison was not only a renowned inventor but also a proficient businessman who earned fame through merchandising his inventions.

