



Surviving the spectrum: inspirational stories
by parents of special needs kids

SPECIAL PARENTS, SPECIAL CHILDREN

in the new norm

EDITED BY
AIDA MOKHTAR AND TANJA JONID

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Special Parents, Special Children in the New Norm - Surviving the spectrum: inspirational stories by parents of special needs kids

Persatuan Sokongan Ibu Bapa Anak-Anak Istimewa (Support Association for Parents of Special Needs Children) (SUPPORT)

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FOREWORD

This book is a special book as I know the editors as colleagues from the International Islamic University Malaysia and friends who have children with special needs. We have been working together on several projects that focus on parents with special needs children and thus, we have common interests in terms of advocating for persons with disabilities (PwDs) to be included in society. We are also part of the informal support group formed in 2018 named the International Islamic University Malaysia (IIUM) Special Parents Support Group that has more than 80 parents who are also staff of the IIUM that have children with various disabilities. COVID-19 has greatly affected all parents with children who have disabilities one way or the other. As a person with a disability myself, I understand that it must be difficult for the children to adjust to life during the pandemic and endemic that come with their own set of challenges. They have had to practice social distancing, wear masks, stay at home most of the day or all day at times with their parents and other family members, that was a difficult time for some.

This book is a collection of the invaluable experiences of parents raising children during the pandemic and endemic as they encounter several episodes of working from home whilst caring for their special needs children at the same time. We can certainly benefit from the sharing of experiences. I know most of the writers well and can empathize with them as I had seen myself the determination, optimism and resilience shown by my own parents through the painstaking journey in raising me up. The amount of patience that they put in and the high level of *tawakkal*, i.e., full trust in Allah's beautiful Masterplan, is truly inspirational which I hold closely in my own vision in life.

Well done to the editors for putting together an extremely important corpus of different stories and to the writers for their contributions that resonate with optimism despite the trying times.

Best wishes!

PROF. DR. RUZITA MOHD AMIN

HEAD,

Disability Services Unit, Office of Deputy Rector
(Student Development & Community Engagement) &

Professor, Department of Economics,
Kulliyah of Economics & Management Sciences,
International Islamic University Malaysia (IIUM)

PREFACE

With regards to COVID-19 as of mid-July 2023, the World Health Organisation (WHO) had reported 767,726,861 confirmed cases and 6,948,764 deaths. The numbers are indeed alarming. The series of lockdowns, the use of face masks, social distancing and home schooling faced by parents in Malaysia encouraged us to adapt to a different kind of life. My son could not attend college and therapy sessions in person which he was accustomed to encouraging us to adapt to the new context.

The editors and authors of this book are parents of children with special needs, that encounter both good times and challenges in life as they raise their children while having careers at the same time. Dr. Tanja Jonid and I as Editors were intrigued by the experiences of these parents during the COVID-19 pandemic, endemic and new norm spurring us to come up with this book. The new contexts have encouraged us to adapt our life to them shaping our problem-solving skills. In events, organisers often welcome parents to share their experiences in raising their children with special needs in person as they are useful for us to learn from and to empathise with, but for this book, the sharing of experiences has been carried out in writing. The compendium of stories from 14 parents strongly echoes the undercurrents of determination, optimism, and resilience felt by them with the hope of inspiring others not to give up and feel let down by the challenges while raising their children with special needs in the new norm.

We hope it is an invaluable read for readers who are facing the same circumstances or for the public who are intrigued to know more of what parents of children with special needs go through in the new norm. The key message of the book is not to give up raising your children with special needs under any circumstances and believe that there is wisdom behind all that happens. Enjoy reading!

Best wishes.

ASSOC. PROF. DR. AIDA MOKHTAR
EDITOR

FOREWORD

The editors would like to thank Prof. Dr. Ruzita Mohd Amin, Head of the Disability Services Unit (DSU) at the IIUM for writing the preface of the book and to all authors, former Senator Datuk Ras Adiba Radzi, Mohd Rashdan Baba, Assoc. Prof. Dr. Azizan Che Embi, Datin Roziyaton Jamaluddin, Dr. Nik Nazli Nik Ahmad, Dr. Wan Rohaida Wan Husain, Dr. Nazatul Akmar Mokhtar, Dr. Zunaidah Mohd Marzuki, Dr. Rozailin Abdul Rahman, Dr. Siti Asma Mohammed and Amran Baharum for their chapter contributions and their willingness to share invaluable insights of their experiences in raising their children with special needs during the new norm. May we all be blessed!

BIOGRAPHIES OF WRITERS

1. **Ras Adiba Mohd. Radzi**

Datuk (Dr.) Ras Adiba Radzi, a former senator of the Upper House in the Parliament of Malaysia, is actively involved in politics. At present, she balances her roles as a mother, wife, poet, politician and athlete. Datuk (Dr.) Ras Adiba Radzi is the founder of the non-governmental organisation, OKU Sentral. She has become a prominent advocate for the rights and well-being of persons with disabilities (PwDs) in Malaysia, using her platform to advocate for them.

2. **Aida Mokhtar**

Dr. Aida Mokhtar is Associate Professor in the Department of Communication, AbdulHamid AbuSulayman Kulliyah of Islamic Revealed Knowledge and Human Sciences (AHAS KIRKHS) and Coordinator in the Disability Services Unit (DSU), Office of the Deputy Rector (Student Development and Community Engagement) at the International Islamic University Malaysia (IIUM). She is Chairperson of the Support Association for Parents of Special Needs Children (SUPPORT) formed in 2023. She has a 24-year-old son with autism.

3. **Tanja Jonid**

Dr. Tanja Jonid is the mother of three amazing boys, one of whom has been diagnosed with dyslexia and the youngest with Autism Spectrum Disorder (ASD). She juggles parenthood with her professional responsibilities as a lecturer and Head of the Department of English Language and Literature at AHAS KIRKHS, IIUM.

4. **Roziyaton Jamaluddin**

Datin Roziyaton Jamaluddin is Chairperson of K-Link Care Center Kuala Lumpur and K-Link Center Jakarta. K-Link Care Center is a non-governmental organisation that provides training programs, therapy and employment opportunities for special needs children. She is also Chairperson of the K-Link Peduli Foundation which is a body that carries out welfare and humanitarian missions for the Indonesian K-Link company.

5. **Nik Nazli Nik Ahmad**

Dr. Nik Nazli is a former accounting professor at the IIUM. As a parent of a 25-year-old special needs son who has a rare chromosome disorder, Dr. Nik also devotes her spare time to support the Selangor and Federal Territory Association for the Mentally Handicapped (SAMH), based in Wisma Harapan, Brickfields. Dr. Nik has served on SAMH's Executive Council since 2017 and is currently in her second term as its Honourable General Secretary.

6. **Hasnah Toran**

Assoc. Prof. Dr. Hasnah Toran is Senior Lecturer at the Faculty of Education, Universiti Kebangsaan Malaysia (UKM). She holds a PhD in Special Education from the University of Birmingham, UK, with extensive experience in early intervention for children with autism and inclusive education. Her research focuses on innovative approaches to special education and lifelong learning.

7. **Wan Rohaida Wan Husain**

Dr. Wan Rohaida Wan Husain is an academic at the Kulliyah of Economics and Management Sciences (KENMS), IIUM. She is the co-founder of Pertubuhan Pendidikan Islam Kanak-kanak Kelainan Upaya Malaysia (PI3KUM), established in 2013. She is also a committee member of the Community-Based Rehabilitation Program (PDK) at the IIUM Gombak campus and SUPPORT.

8. **Nor Azizan Che Embi**

Assoc. Prof. Dr. Nor Azizan Che Embi is an academician who began to be involved with PwDs since being a volunteer for students with eye impairments while doing her Master's degree. She is blessed with lovely children and her eldest has multiple disabilities. Currently, she is involved in the establishment of IIUM's PDK and is Treasurer in SUPPORT.

9. **Mohd. Rashdan Baba**

Haji Mohd Rashdan Baba also known as Pak Dan is Senior Library Assistant in Dar Al-Hikmah Library of the IIUM. Experienced in managing Sahabat Faqeh @ IIUM; that offers weekly classes on Al-Qur'an and Fardu 'Ain for the deaf. He is currently affiliated with SUPPORT as Assistant Secretary. A husband to a super wonderful wife with four fabulous children. Alhamdulillah!

10. Nazatul Akmar Mokhtar

Dr. Nazatul Akmar Mokhtar is currently working as a lecturer at the Kulliyah of Education, IIUM and specialises in Curriculum and Instruction, Teaching Thinking and Value Education. Having a special needs child (cerebral palsy) has indeed enlightened her on the need for the special education system to be improved further. She also hopes to play her role in educating the society to understand better on special needs children by sharing her experiences

11. Zunaidah Mohd. Marzuki

Dr. Zunaidah Mohd. Marzuki is academic specialising in Islamic scriptural sciences, i.e., Qur'an and Hadith studies at the Department of Qur'an and Sunnah Studies, AHAS KIRKHS, IIUM. Her keen interest is in advocating about disability issues mainly because she learned about the challenges and opportunities of raising her cerebral palsy son.

12. Rozailin Abdul Rahman

Dr. Rozailin Abdul Rahman is a mother to four children. Two of them have disabilities, including speech delay and mild autism. She is originally from Pontian, Johor and has been employed as an academic since 2006, first at the IIUM and then at Coventry University, United Kingdom (UK). To further develop her academic career and discover greater educational opportunities for her two special needs children, she moved to the UK.

13. Siti Asma Mohammed

Dr. Siti Asma is a devoted mother raising her child with mild to moderate autism. Balancing the challenges and joys of raising her child, her journey reflects both resilience and compassion, as she works to create a nurturing environment for her child and promotes inclusivity to help others understand and navigate the challenges of autism.

14. Amran Baharum

Amran Baharum is a former academician in the Department of Communication, AHAS KIRKHS, IIUM. His journey as the father of a special needs son, Muhammad Naqiuddin, started in August 1989 when Along Odin was born in Kuantan, Pahang. Diagnosed as a slow learner, currently, Along Odin has no problems in using public transportation and continuously improving himself. May Allah bless him.

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