

A Pictorial Journey into the Lives of Persons with Neurodevelopmental Disabilities

LIVING ON THE MARGINS

A Pictorial Journey into the Lives of Persons with Neurodevelopmental Disabilities

The Pictorial Booklet is an output of the research A Study on Status of Health, Education and Employment among Persons with Neurodevelopmental Disabilities in Bangladesh

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Published by **BRAC James P Grant School of Public Health**BRAC University, Bangladesh

10-13 Floor, BRAC Tower, 65 Mohakhali Bir Uttam A K Khandakar Road, Dhaka-1212, Bangladesh.

First Published July 2025
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DEDICATED TO

All the participants who shared their narratives

BRAC James P Grant School of Public Health (JPGSPH), BRAC University conducted a mixed-method study in collaboration with Apasen International, a UK based charity organization working for persons with neurodevelopmental disabilities. The study was titled- 'Status of Health, Education and Employment among Persons with Neurodevelopmental Disabilities in Bangladesh.' The study included 414 persons with neurodevelopmental disabilities, covering 40 sub-districts (upazilas) across 33 districts within the eight administrative divisions of Bangladesh.

All the information used in this pictorial booklet is based on the findings of the study.

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Acknowledgements

We thank the Department of Social Services (DSS). Neurodevelopmental Disabilities Protection Trust (NDDP Trust), Directorate General of Health Services (DGHS), and other government agencies for their support during this research. We also appreciate the guidance and encouragement from Dr. Laura Jean Reichenbach, MPA, ScD, Dean of BRAC James P Grant School of Public Health (JPGSPH), BRAC University; Prof. Ahmed Mushtague Raza Chowdhury, Advisor at JPGSPH, **BRAC** University, and Mahmud Hasan, MBE, Chief Executive of Apasen International; and Advisory Board Members of Apasen International during the study. This work is a collaborative effort between Apasen International and the BRAC JPGSPH, BRAC University.

Message from the Dean

BRAC James P Grant School of Public Health (JPGSPH) BRAC University



We are pleased to publish this booklet, "Living on the Margins: A Pictorial Journey into the Lives of Persons with Neurodevelopmental Disabilities." This booklet shares stories of individuals with neurodevelopmental disabilities in Bangladesh that highlight the systemic discrimination and stigma they face in society and how many of them successfully overcome these challenges to achieve success in their personal and social lives. The booklet aims to increase awareness and understanding about disability and disabled people among the general public by sharing the lived experiences of persons with

neurodevelopmental disabilities, their resilience. and their contributions to building a just society.

At BRAC JPGSPH, BRAC University, we are dedicated to promoting equity and iustice through research and practice. This initiative reflects our mission to prioritise the needs of marginalised populations and support evidence-based solutions that enhance lives.

We are thankful to Apasen International, our valued partner, for their ongoing collaboration and commitment to disability rights. Special thanks to Dr. Md. Tanvir Hasan, Principal Investigator of the research

project, and his devoted team for their hard work in making this study possible. I also appreciate my colleague Arifa Bente Mohosin for leading the effort in preparing this booklet with thoughtful writing, which brought the stories of individuals with neurodevelopmental disabilities to life.

Finally, we thank the participants and their families for sharing their experiences with honesty and courage. Their voices are vital for shaping inclusive policies and services

Laura Jean Reichenbach, MPA, ScD

Dean

BRAC James P Grant School of Public Health, BRAC University

Message from the Chief Executive

Apasen International



It is with great pride and humility that we present this pictorial booklet, which documents the lived realities of persons with neurodevelopmental disabilities in Bangladesh. These visual and narrative testimonies speak volumes not only about the challenges that individuals face in accessing health, education, and employment—but also about their extraordinary resilience, creativity, and dignity.

At Apasen International, we believe that visibility is the first step to inclusion. This booklet does not merely depict hardship; it reveals strength, courage, and

potential. The images and stories shared here remind us that inclusion is not an act of charity— it is a matter of rights, of choice, of justice, and of shared humanity.

We are deeply honoured to have partnered with the BRAC James P Grant School of Public Health on this journey. I extend my heartfelt thanks to all the participants who bravely shared their stories and to the entire research team for capturing them with such care and integrity.

Let this publication serve as a powerful call to action—for policymakers, practitioners, communities, parents, and carers—to build a more inclusive world where no one is left on the margins.

Mahmud Hasan MBE Chief Executive Apasen and Apasen International

Message from the Principal Investigator

BRAC James P Grant School of Public Health (JPGSPH) BRAC University



Persons with neurodevelopmental disabilities are among the most marginalised groups in society. According to the Rights and Protection of Persons with Disabilities Act 2013 and the Neurodevelopmental **Disability Protection Trust Act** 2013, there are four types of persons with neurodevelopmental disabilities in Bangladesh: Autism Spectrum Disorder, Intellectual Disability, Down Syndrome, and Cerebral Palsv.

Stigma surrounds neurodevelopmental disabilities, and individuals with these conditions often face discrimination when accessing healthcare, education, and employment opportunities. Many of them succeed in overcoming challenges and achieving success. However, due to stigma and fear of discrimination, many withdraw from accessing these opportunities.

This pictorial booklet, written by my colleague Arifa Bente Mohosin, shares real-life stories of persons with neurodevelopmental disabilities in Bangladesh. It highlights their unique challenges, along with positive stories, necessary system changes, and inclusive practices.

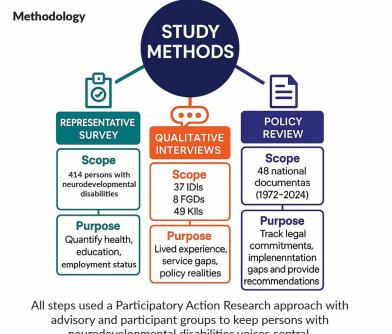
I would like to thank our partner, Apasen International, for their support during the research. I also sincerely acknowledge the support from the Ministry of Social Welfare, other ministries and our advisory groups; without their assistance, this research would not have been possible.

I hope this booklet will contribute significantly to safeguarding the rights of persons with neurodevelopmental disabilities and assist policymakers, educators, and society at large in building an inclusive community.

Md Tanvir Hasan, PhD Associate Professor BRAC James P Grant School of Public Health, BRAC University

Aim of the study

The aim of the study was to assess the health, education, and employment situation of persons with neurodevelopmental disabilities in Bangladesh, identify the contextual barriers they face, explore government and non-government initiatives and policies, and provide recommendations to their health, well-being, improve education. socio-economic conditions.

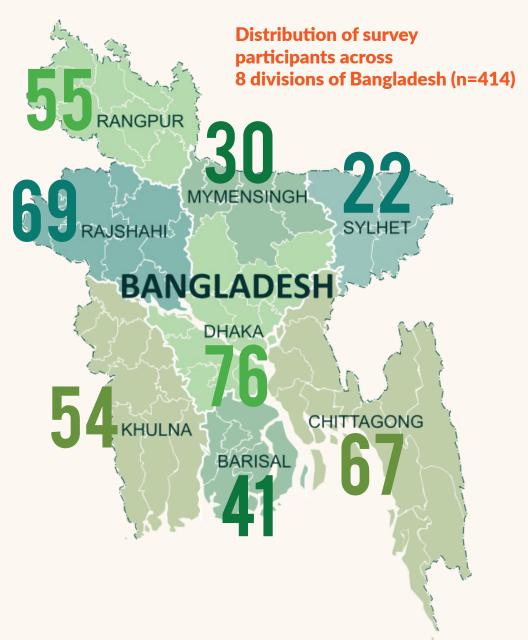


Background of the Research Participants

This section introduces the study participants who shared their stories that are the heart of this pictorial booklet. Each participant's journey shows how disability related stigma and discrimination affect their access to health. education, and employment, while also showing their determination to live with dignity.

The study included 76 individuals with neurodevelopmental disabilities from Dhaka, followed by 67 from Chittagong, 69 from Rajshahi, 55 from Rangpur, 54 from Khulna, 41 from Barishal, 30 from Mymensingh, and 22 from Sylhet. All four types of persons with neurodevelopmental disabilities were represented in the study population.





Among the 414 survey participants



33%

Had Intellectual Disability

Intellectual disability refers to significant limitations in intellectual functioning and adaptive behaviour, typically indicated by an Intelligence Quotient (IQ) below the normal range.

Among the 414 survey participants



29%

Had Autism or Autism Spectrum Disorder

A neurodevelopmental condition marked by difficulties in social interaction, communication, and repetitive behaviours, often with sensory sensitivities or unique strengths.

Among the 414 survey participants



28%

Had Cerebral Palsy

A neurological disorder caused by early brain injury or disease, leading to movement and posture challenges and often accompanied by sensory, cognitive, or communication impairments.

Among the 414 survey participants



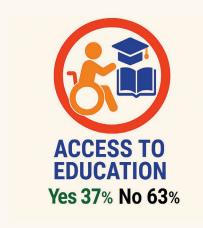
10%

Had Down Syndrome

A genetic disorder caused by an extra 21st chromosome. characterized by intellectual disability, distinctive physical features, and potential health

Status: Health, Education & Employment









Anila's Journey to Mental Well-Being

Anila is a 26-year-old woman living with cerebral palsy. She cannot stand or walk and relies on a wheelchair for mobility. Both of her hands are bent and stiff, so she needs help to move her wheelchair and cannot do tasks on her own. Anila lives with her parents in Dhaka, where they run a school for children with disabilities. She comes from a well-off family and has completed her law degree from a respected private university in Bangladesh.

Anila regularly visits hospitals for treatment. Her parents support her with great love and care. Reflecting on her mental health. Anila shared a hurtful memory from her childhood. A female teacher who tutored her once visited their home with her child. The child asked why Anila's hands were bent. The teacher told him that God made Anila's hands like that because she misbehaved a lot and warned the child not to be mischievous. Although Anila felt very sad, she didn't say anything then. She believes her teacher did not understand disability. She is also aware of the social stigma and the negative attitudes toward disability that she and her parents face every day. She admires her parents for being mentally strong and for believing that she is a gift from God. They try to show strength and not let others see their worries. However, Anila admits that she herself sometimes feels



weak, frustrated, and worries about her health condition.

Anila shared that she is gaining weight due to thyroid medicine and cannot exercise. She is worried that those who help carry her, especially her father, will face difficulties because of her growing weight. She depends on him for mobility and physical support.

Anila has no social life and no friends. She says, 'I do not have any friends, and that hurts me.' In family gatherings, she notices the difference in her life compared to her cousins who are getting married. Her friends also share photos from outings and trips without her, saying 'we are all together,' but Anila is not included. She feels left out

and saddened. She knows that people with cerebral palsy can understand everything around them but cannot always participate due to physical limitations. When her friends are out socializing. she is usually at therapy or treatment sessions. These experiences make her feel very sad.

Anila has observed how parents of children with disabilities face stigma too. Her mother, for example, has cut down on social gatherings because people make hurtful comments about Anila. This damages the family's mental health and adds to their isolation.

Anila also believes that while it is possible for men with cerebral palsy to marry, it is much harder for women. If a woman with cerebral palsy marries, her family life often becomes difficult. Because society expects women to fulfil certain gender roles, a woman with

cerebral palsy may face divorce or broken relationships if her husband and in-laws are not supportive or understanding of her needs. This may negatively affect her mental health.

To cope with these challenges, Anila suggests that people seek counselling and see psychiatrists. However, she points out that in Bangladesh, many people avoid consulting mental health professionals out of fear of being labelled as mentally unstable. This stigma prevents people from getting help and can worsen their depression. Anila believes that early diagnosis and treatment can help, and that people with cerebral palsy-and their families-need to advocate for their rights and acceptance in society. In her words, 'No one will accept them unless they make themselves accepted.'



"

Anila's story reveals how family support and mental health care are crucial for the resilience of persons who have physical difficulties, underlining the importance of expanding community-based mental health services and family support programmes.



Marziya's Pursuit of Education: Overcoming Challenges

Marziya is a 19-year-old girl with mild autism. She has no physical symptoms of disability. She lives with her parents, grandparents, and two brothers in a financially struggling household. Her father and grandfather work as farmers on their own land. while her older brother is a tailor. Marziya's family faces economic challenges, which have made it difficult for her to access extra educational support.

Marziya sat for her Secondary School Examination this year but failed in mathematics, a subject she finds difficult. She hopes to retake the exam, but she could not afford private tutoring because of her family's financial condition

Her school is a ten-minute walk from her house and has both boys and girls. Marziya has four close friends there, all of them girls. She is shy and avoids talking to other classmates and teachers, who often scold her for not responding to questions about her schoolwork. Some of her peers tease her about her disability, which makes her feel even more isolated. As a result, she rarely shares her feelings and tends to keep to herself, although she sometimes joins in games with her friends. 'If anyone calls me disabled. I feel like crying. I cannot tolerate it,' she says. Even though she has these difficulties, she makes an effort to focus on her studies.

At home, Marziya has a good relationship with her mother and sister-in-law. She shares her feelings mostly with her mother but tends to guarrel with her brothers. When she feels pressured to help with household chores. she sometimes locks herself in her room, cries, and refuses to eat until her mother comforts her. Despite these challenges, her family members love her, especially her father.

Marziva has never been taken to a hospital for her disability. She only visits nearby health facilities when she has general health issues. like asthma. She has not received any formal support or accommodations for her condition in school.

Recently, Marziya

became engaged. Although she once believed she would never marry due to her disability, she is now excited about her future. Her husband, who owns a small tailoring shop, has promised to let her continue her studies. This promise has given Marziya new hope. She dreams of becoming successful in life and wants to prove that she can overcome the barriers she faces.

Marziya's journey shows that inclusive education and supportive communities help persons with neurodevelopmental disabilities reach their potential, emphasizing the need to integrate inclusive policies and train teachers to support diverse learning needs.



Atiya's Path to Learning, Creativity and Recognition

Atiya is a 26-year-old unmarried woman with autism. She does not have any visible physical disabilities, but she experiences some challenges with fine motor skills. For example, she finds it difficult to cut vegetables with a knife, and both of her hands tremble slightly when working. This tremor is minor, and she receives therapy for it at the SWID Bangladesh Therapy Centre. Atiya comes from a middle-class family and lives with her parents and elder sister. Her father is a businessman, her mother is a housewife, and her sister is currently pursuing her graduation.

Atiya began her education in a private general education school. However.

after a few years, her parents noticed limited academic progress and decided to transfer her to SWID Bangladesh School in 2009. Since then, she has been continuing her education there in a more supportive and inclusive learning environment. Over the years, she has made steady improvement in both academic and functional skills.

She is currently enrolled in the girls' section of the **Vocational Training Centre** (VTC), where, in addition to her basic education, she actively participates in various skill-building and creative activities. These include learning Islamic songs, drawing, cooking, and jewellery making-areas where she continues to develop confidence and express herself.

In 2018, during Eid-ul-Azha, Atiya participated in a national drawing competition held at the Prime Minister's Office. She won the first prize and received 100,000 taka [approximately 818.13 USD] for her Eid-themed artwork. Her drawing was selected for the official Eid cards used by the Prime Minister to send formal greetings.

Atiya is also an active member of the girls' scout group. Through this group, she had the opportunity to perform a solo Islamic song on a television programme that was aired on Bangladesh Television (BTV) in 2023.

Although Atiya has

limited formal academic qualifications, she is a dedicated learner and shows strong enthusiasm for extracurricular activities. She is especially passionate about singing and dreams of performing more frequently on television. In her own words, 'I want to be an Islamic singer. I want to work with BTV more. If I get the chance to sing there regularly, I would be happy. This is my dream.'



Atiya's story reflects the importance of inclusive education and vocational training in supporting persons with neurodevelopmental disabilities to build confidence, showcase their talents, and pursue their aspirations.

CASE STORY 4





"I used to feel sad when no one wanted to play with me."

The Burden of Stigma in Continuing Education of Pallab

Pallab is a ten-year-old boy who lives with his parents in a small village near a border area. He was born with cerebral palsy, which caused both his legs to be twisted. This makes it hard for him to walk, but Pallab never gives up. He walks slowly, leaning on things for support.

At school, Pallab faces stigma and discrimination. Many of his classmates laugh at him because of his legs. Some parents tell their children not to play with Pallab or be his friend. At first, the school did not want to accept him because there was no special school for children with disabilities in his village. So Pallab had to go to the regular school, even though it was not easy for him.

Pallab often feels lonely. He said. 'I used to feel sad when no one wanted to play with me.' While other children run and play, Pallab stays alone. But he has learned to find joy in other things, like playing with the chickens and hens around his house.

Pallab's teachers did not believe he could keep up with the lessons because of his disability, telling him 'You won't be able to succeed here.' But Pallab worked hard and proved them wrong. Over time, his teachers saw that he had potential and started to support him.

When he was younger, Pallab went to a hospital in Dhaka for treatment, but the doctors said there was little hope. His parents were very

sad. His mother said, "We tried everywhere in Bangladesh, but no one could help him." Finally, they took Pallab to Kolkata, where he had surgery and therapy. After months of hard work, he learned to stand and walk with support. His parents helped him practice his exercises every day.

Even with all the challenges, Pallab is strong and hopeful. He wants to study and become someone important one day. Although he still feels sad sometimes when children do not want to play with him, he does not let it stop him. Pallab keeps moving forward, step by step.

"

Pallab's journey illustrates how children with cerebral palsy face stigma and discrimination in education, yet his perseverance and family support highlight the urgent need to ensure inclusive schooling and remove barriers so that every child can thrive.





Samad's Journey Toward Skill Development and **Economic Empowerment**

Samad is a 24-year-old young man with cerebral palsy who faces significant physical challenges. His right hand and leg are inactive, and he has weak vision in his right eye, causing him to see double and experience blurred vision when focusing on writing or using a computer for long periods. He can walk without support but cannot use his right hand for any tasks. Despite these difficulties, Samad has shown great determination to build a successful career. Samad lives with his parents and two younger sisters. The family's financial situation is modest. His mother is a housewife, and his father works as a day labourer.

When Samad was 3 years old, his family noticed visible symptoms of disability and took him to Sylhet Medical College, mainly because of issues with his leg. Doctors said that surgery might have helped if they had come earlier, but now they couldn't say for sure, it might not help and could even make things worse. Due to this risk, Samad's family decided not to go ahead with the surgery. He was given special leather shoes and taught some exercises, but these didn't bring much improvement. The hospital did not recommend any further therapy.

Samad's strong will and ambition have driven him to seek training opportunities that would help him become financially independent and support his family. He has

completed several vocational training programmes, including a six-month basic computer application course at the National Youth Development Institute and a 15-day leadership management course at the Sheikh Hasina Youth **Development Centre in** Dhaka. These training experiences equipped him with valuable skills that he could put to use. With the knowledge he gained, Samad established a computer training centre that can train up to 12 students at a time. The centre offers basic computer application courses, with course fees ranging from 1,000 to 3,000 taka [approximately 8.18 to 24.54 USD] for a three-month programme.

Certificates are provided to graduates, and so far, six batches have completed their training and found jobs in various offices. This centre, named Holy Youth Development Training Centre, is a branch of a larger youth training initiative. In 2024, Samad's branch was awarded the best training centre of the year. From his training centre. Samad earns between 8,000 to 10,000 takas [approximately 65.45 to 81.81 USD] per month. He also provides services related to voter ID cards and birth registrations, further contributing to his family's income. His hard work and dedication have not gone unnoticed; he received an award as the best training facilitator from the Islamic Relief Foundation. Samad's journey is a testament to his resilience and ambition. In his words, 'My dream is to continue growing as an entrepreneur and encourage others to achieve their own goals in life.'

Samad's story highlights how access to vocational training and entrepreneurial support can empower persons with neurodevelopmenta I disabilities to achieve economic independence. His journey shows the importance of inclusive skill-building opportunities and recognition of diverse abilities in the workforce.

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Rony's Path to Employment and Independence

Rony is a 45-year-old unmarried man with Down syndrome. Although he does not have significant physical challenges from his disability, he does struggle with obesity. His parents are very elderly and unwell, and they live separately from him. Rony's siblings are already settled in their own lives. Coming from a higher-class family, Rony currently lives in a residential home managed by SWID Bangladesh.

Rony deals with various health issues. He has diabetes and manages it by taking insulin and regular medication. He visits BIRDEM for his check-ups. He also suffered a severe injury that led to broken leg, requiring surgery and a long recovery. He spent more than eight months in a trauma centre and was in some coma for a period. Fortunately, he recovered, although he still struggles to walk and uses a walker to move around. He experiences ongoing pain in his legs and attends therapy sessions regularly.

Ronv studied at SWID Bangladesh's office, where he received vocational training to become a small entrepreneur. After completing his education up to class five, he joined the office as an assistant. Rony has worked at SWID Bangladesh for over ten years. His monthly salary is 5,000 taka [approximately 8.23 USD]. He spends 1,000 taka [approximately 41.15 USD to support his parents and another 1,000 taka

[approximately 41.15 USD] for his own needs. He saves the remaining money in a bank account for his future. Rony is content with his work, although he wishes his salary could be increased. He feels well cared for by the NGO's director, who supports him and looks after his health.

Rony has friends in the home where he lives. He is independent in his daily activities, but sometimes conflicts arise with other residents. Some of them tease him by saying hurtful things like, 'Your other leg will also get broken.' Once, he was falsely accused of stealing 2,000 taka [approximately 16.46 USD]. This accusation made him very upset, and he stopped eating for a while.

However, he tries to manage his anger and reminds himself to stay calm and behave well. Rony enjoys listening to music when he feels sad. At times, he feels deeply frustrated and says 'I feel very sad. I feel like suicidal.' But he finds comfort in knowing that the NGO director supports him. Rony respects the director a lot.

Rony wants to succeed in his work and believes that everyone with Down syndrome should make efforts like he does. His goal is to keep trying and prove that people with disabilities can lead independent, meaningful lives. He says, 'I want to show others that someone with a disability like me can achieve success in life.'

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Rony's story underscores how inclusive employment and supportive workplaces empower persons with Down syndrome to lead independent lives, showing the value of developing inclusive employment policies, accessible workplaces, and fair wages. 77



Tuhin's Experience: An Unexpected Act of Workplace Violence

uhin is a 30-year-old man with an intellectual disability. He does not have any physical difficulties. Recently, Tuhin got married, and he feels very happy about this new chapter of his life.

Tuhin works as an office assistant at the SWID Bangladesh office, where he handles clerical tasks. He is well-liked by everyone in the workplace. However, he did face an unpleasant incident involving harassment. Tuhin shared the incident:

"One day at work, an employee asked me to go inside the office because there was construction work going on. Although he might have been worried about my safety, he spoke to me in a rude manner. I told him I would go inside after finishing a small task, but he insisted and said.

'Leave now, I say.' Then he hit my leg with a stick. I became angry, and we started fighting until others stepped in and stopped us. Later, I filed a complaint with the office management. The employee apologized to me and said, 'Please forgive me. I made a mistake.' He also paid a penalty of fifteen thousand takas. In the end, I also apologized to him."

Tuhin's experience shows that even in supportive environments. persons with intellectual disabilities can face workplace violence, highlighting the need for protections. accessible complaints. inclusive training. and coping support to promote safety and resilience.

Way Forward

Persons with neurodevelopmental disabilities face significant barriers, yet they demonstrate remarkable resilience in pursuing their rights and aspirations. Their stories highlight not only personal strength but also expose critical gaps in the systems meant to support them. To facilitate their inclusion and well-being, targeted improvements in health, education, and employment services are essential.

 Anila's story underscores the psychological burden faced by individuals and their families. Accessible mental health services and community-based

- support systems should be strengthened to promote resilience and social inclusion.
- Atiya's story highlights the importance of inclusive, skills-based education for young women with neurodevelopmental disabilities. Expanding access to creative and vocational training within special schools can help unlock hidden talents and boost confidence.
- Pallab's and Marziya's
 experiences highlight the
 need to address stigma in
 schools and train
 educators to support
 diverse learners. Inclusive
 education should be part
 of regular teacher
 development
 programmes, and

- awareness should be raised among communities and school authorities to foster acceptance.
- Samad's experience shows how targeted vocational training and entrepreneurship support can empower persons with neurodevelopmental disabilities.
 Community-based training initiatives should be scaled up and linked to income-generating opportunities and recognition systems.
- Rony's and Tuhin's stories show how access to employment brings dignity, but also reveal risks of exclusion and harassment. Employers should ensure safe, inclusive workplaces and fair pay.



All photos and life stories shared in this booklet have been published with the full consent of the participants. We deeply respect their contributions and thank them for allowing us to share their experiences.

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My advice to other disabled people would be, 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. Stephen Hawking



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