

# Preface

This book is the outcome of a long and ongoing journey, which has seen moments of extreme fear, doubt and loneliness along with immeasurable joy and fulfilment. As any parent will testify, raising a child with disability is an adventure into the unknown. There is an old and oft repeated story told to parents of children with disability about booking a holiday to Italy and finding oneself in Holland instead; a circumstance that could be seen as either as a disappointment, or as an opportunity to explore the unanticipated, the unexpected, and find value and beauty in it. My encounter with autism has been one such experience; opening my mind to the possibilities and promise of different subjectivities and ways of being in the world; strengthening my belief in the unity underlying all diversity and shoring up my commitment to leave this world a better place for those who cannot engage with it on the same terms as the so-called ‘normals’.

I have been lucky to find fellow-travellers in this journey who have shaped my understanding about disability as an axis of discrimination rather than as a fate worse than death; who have taught me about the intrinsic worth of all human beings regardless of (in)ability; and inspired me to transform my personal experience into a shared resource that can make visible to the community the day-to-day realities of families of persons with complex and challenging disabilities. This book is a sincere attempt to bring to light an issue that is frequently neglected by mainstream academic discourse and to engage with it not merely as a personal problem, but as a reflection of fundamental changes underway in the society. Families are not just providers of care but also a potential source of social change; their engagement with their children can open a window through which the rights and personhood of people with disability are fostered and protected. At the same time, these families desperately need support, both material and moral, and above all a sense of reassurance that their loved one with disability will continue to receive the care that (s) he needs even after the parents are gone.

This book aims to bring to light the stories of families of children with autism as they struggle through the often daunting journey of coming to terms with their children’s difference and their sometimes extremely complex and challenging needs.

It locates these life stories against the backdrop of a fast changing and often unforgiving urban milieu where traditional systems of support are no longer readily available and new avenues and opportunities are coming into being. It attempts to document the advent of new forms of mobilizations based upon a shared experience of crisis that has the possibility to change society for the better; to inaugurate a more humane and inclusive order.

I thank the families who shared their stories with me and thought me worthy to be their interlocutor; with deep humility, I dedicate this book to them and to all our children with autism. Merry Barua and her magnificent team at Action for Autism, New Delhi, have been sources of inspiration, succour and friendship to countless parents; thank you is an utterly inadequate term, but unfortunately, I know no other! Professor Nilika Mehrotra, who supervised the doctoral research on which this book is based, introduced me to the field of disability scholarship and was always most generous with her time, sound advice and academic guidance. I owe a debt of gratitude to all my teachers at the Centre for the Study of Social Systems, Jawaharlal Nehru University, New Delhi, for their support and encouragement over the years. I express my gratitude to my colleagues and co-workers at the Indira Gandhi National Open University, for providing the opportunity and a congenial environment for pursuing my research interests and academic pursuits.

For her faith in the manuscript and ensuring that this book sees the light of day, I thank Shinjini Chatterjee, my editor at Springer. Her insightful comments and suggestions contributed greatly to the book. Thanks are due to the anonymous reviewer for the close reading and valuable comments.

I thank my sons Vibhu and Vishu for coming into my life and making it special. Our journey together has not always been smooth sailing, but they have borne the difficult times with remarkable fortitude and enjoyed the good ones with tremendous joie de vivre. Last, and by no means least, I thank my wonderful circle of friends for their love, support and camaraderie; for always believing in me through the good and bad times.

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