



Backer's
Autism is Different

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PREFACE

Autism is a fascinating term except for the parents of the autistic children.

Though the likes of Dr. Leo Kanner (1943) and Dr. Hans Asperger (1944) have independently described the phenomenon, there is still wide spread differences in perception among the professionals as well as the public regarding what forms autism. As the



paediatric neurologist Alency Percy says, “our understanding of it (autism) is sort of like the fable about the blind men describing the elephant. What part you look at determines what you see”. For doctors, autism is a clinical dilemma. Even though the diagnostic and statistical manual has set forth diagnostic criteria for diagnosing autism, doctors find it difficult to commit to a diagnosis in the absence of a diagnostic test (like blood test) or brain scan. Eventually most of the doctors talk about ‘autistic features’ in a child avoiding a definitive answer. Despite this, there are some professionals who offer a definitive ‘cure’ for autism!

Since communication forms major issue in autism, speech therapist finds autism interesting. As behavioural issues are common among these children, various techniques are available for experimentation. Teachers prefer to label the autistic children as ‘retarded’. The one who pays for all this is the parent who gets exhausted physically, psychologically and financially. The child, who is at the centre of all this, grows with the feeling that there is some serious issue with him which calls for investigation and fixing. The resultant loss of self esteem makes these children feel that they don’t ‘fit in’ in this society.

Fortunately lot of information is pouring in from researchers and adults with autism. Autistic savants like Daniel Tammet and Sue Rubin have vehemently opposed the traditional IQ Assessment methods which were quick to label the child as retarded. Eminent autistic persons like Temple Grandin, Donny and Kyle contributed their mechanical, calendarical and mathematical talents respectively. Savants with music and artistic talents are innumerable. Many studies have shown that 10% of autistic people have savant skills and half of the people with savant skills are autistic.

This book, ‘Autism is Different’ primarily serves to underscore the positive dimensions of autism. My professional interactions with colleagues, students and parents have hugely contributed to the areas that form parts of the book. The first part of the book carries chapters on brain and savant skills in autism. The second part shifts the focus to parents who are at the receiving end, under constant stress, burdened with task of rearing the autistic child. The final part which dwells on the management of autism, will be equally helpful to the professional as well as the parents.

‘Nothing about us without us’ is a slogan that came into use during 1990s to emphasise the message that the voices of those affected by the problem must be heard while analysing the problem. This justifies my inclusion of quotes, lengthy statements and even chapters by noted autistic figures like Temple Grandin, Rachel Cohen Rottenberg and Stephen Shore. Equal thrust is provided to narratives from the parents and professionals of different fields. The repetitions which might have crept in, in this attempt to provide a wide cross section of first hand narratives, may be ignored.

The professionals have the habit of seeing any problem as a tragic personal condition which necessitates the services of (primarily medical) professionals. Very often service providers make decisions for autistic people with the assumption , “oh this person really doesn’t understand this situation. I’ll help them”. Parents, on the other hand, do understand the situation almost always. But their opinion and priorities will be different from those of the service providers. This is what leads to the creation of a self- fulfilling prophesy and parents are told that they can’t take care of themselves and they gradually begin to believe this. This, in turn, forces the parents to run for more services. This paternalising creates dependency which allows paternalism to continue. Dependence creates poverty, isolation, indignity, powerlessness and marginalisation, all of which, again, allow paternalism to continue.

The only way out of this vicious circle is to reject paternalism. For this to happen, we need to empower the parents. Parents should be the power house - willing to believe when others doubt, willing to act decisively for the child while those around refuse to support, willing to seek help from outside and to be firm and focused in the face of opposition. This liberates parents from the clutches of self fulfilling prophesy - of helplessness, familial victimisation, professional service providers decrees, and , importantly, of social isolation. The answer doesn’t lie in paternalism, but in independence, integration, empowerment, self help and self determination.

Once autism is diagnosed, you cease to be a parent. You turn into a case agent. You are a manager. You are an education specialist. You learn to figure out the medical system. The dual task of advocating the system and navigating it is indeed overwhelming. But it is only the parent who genuinely care for their children. They are the only ones who are intrinsically motivated to know it all, try it all. They pay for their children’s education and for the research. They are the truly autism specialists. The rest is waste of time.

Autism excites always. The news of autistic children exhibiting extraordinary (often savant) skills comes from different parts of the world day after day. Information is at anybody’s fingertips. With the help of functional MRI, neurologists are working on autistic brains to see what is happening.

This book is the second edition. The contents remain mostly the same except for elaboration on sensory issues in autism. I reiterate that I will be much obliged to persons who can contribute, criticise or correct me in any of the areas that have been covered in this book. I have collected informations in the best interests of parents and persons with autism and will be most happy if anybody is willing to translate this book in any of the local Indian languages.

Dr. C. P Aboobacker

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