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Understanding Autism: Parents, Doctors and the History of a Disorder

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This book will provide the reader with an account concerned not only with the history of autism as a diagnostic category of humans, but with how people have sought to respond to and shape our understanding and its meaning. Chloe Silverman has written an eloquent and scholarly account of autism that is also deeply humane and accessible, upfront unflinching in its focus on the ferocious love of parents and others that over the decades has resulted in the narrative of autism being heard loudly. Silverman does not shy away from the darker corners of history (there is no revisionism here: Wakefield and Refrigerator Parenting are solemnly discussed), but the well written text is at all times respectful of the voices she has listened to, even for those words we today find challenging to hear.

The book skilfully outlines how our understanding has grown through not only the research into all things autism, but through the experiences of parents themselves. Silverman has threaded throughout her informative book ethnographies of families and groups of people sharing their learning, and suggests not only is love not sufficient, but neither is science. Together, however, they make individuals and groups mightily powerful. Lovaas, as Silverman notes, emphasised the need for full parental involvement in behavioural programmes.

The determination derived from love to do what works often makes all the difference. It is love that carries parents through difficult periods, that ensures things get done, that tempers the excesses of science. It is love's keen gaze that obliges parents to watch closely, listen well, think deeply; and such accounts, drawn from deep involvement, inform what others, not so close, should consider in their research and their advice. Silverman balances the good, the bad and the ugly tales of psychodynamic and behavioural approaches, and it is to parents, as para-professionals, as expert amateurs, to whom Silverman turns when seeking an understanding of how the wonders and dismays of life within and alongside autism are navigated.

Silverman is never sentimental; love is a steely drive toward the future, not a meandering picnic by the scenic roadside. It pulls no punches. Here love is not soft but determined. Silverman cites widely not only the scientific literature and debates but the voices of parents and professionals to illustrate the role of love in making or breaking our endeavours, and the author is powerfully aware of the need for love to affect doing: she cites Maurice's *Let Me Hear Your Voice* eloquent description of the difference between parent and professional: “they, with their clinical distance, were comfortably resigned; I was torn apart. Worse, they could delude themselves, with their degrees and their windy verbosity, that they were ‘helping’. I could afford no such pretensions” (Maurice, 1993, pp. 56-7, cited by Silverman, 2012). Making situations parents might not have chosen work well, regardless, is what love does. Parental love is most profound when not dogmatic but practical.

The author finds evidence of love in the tendency of people to hold fast to at least two contradictory ideas at the same time: both an acceptance of the individuality of the person with autism and a compelling drive to “free them from restrictions that their impairments impose on them” (p. 236). There is both fear and beauty in diversity, and both doubt and surety. Such sometimes uncomfortable stances are not the domain of pure science or numbers alone but of love and faces. Silverman concludes that such devotion of parents “impels us to consider the object of our love as both a biological being, subject to manipulation and harm, and a person, precious and complete in his or her own right” (p. 236).

Imagine going on holiday to a foreign land, a place where the language and norms are a little bit at odds with your own. After a little while you become more familiar with how people speak, what people do, and you begin to pick up on the cadences of meanings. You stumble down a dark alley and discover a brightly lit restaurant. With your face pressed against the glass you can make out a memorable scene: people inside are involved in a seemingly chaotic social gathering – people gesticulate as they eat, you see dish after dish on the table, and each looks succulent and inviting. There are jugs of wine and water, and you can make out the echoes between laughter and tears and shouts and sighs, you can see people eating heartily. They are sharing in something formidable. A local wanders up beside you and presses his nose to the glass and, aware of your wishful expression, begins to explain in broken English what the people inside are eating, what they are doing, why they are there, how what they are eating is seasoned, what it tastes of, what they can expect by way of dessert and, most importantly, tells you how to make your way inside. You try to get inside but the door is locked. He wanders off having offered his considered local opinion.

I suspect the autism spectrum is a bit like this; those of us considered neurologically typical (a questionable category, I know) may look at the world and culture of the autisms and ponder what it feels like, tastes like, and is like, as a lived experience. Guides will appear from time-to-time and give us their interpretation of what they too witness from outside, but the thing is, unless one belongs, unless one experiences, our accounts are acts of interpretation, descriptions of what we can see. We can neither taste nor share. Silverman does not claim to show what people experience inside; she does however suggest the need to combine objective accounts of the meal, with an empathy for the experiences in there.

Silverman's book, then, is written from the perspective of “a sympathetic outsider” (p. 232) rather than a parent or “expert in autism,” and so brings some several degrees of useful separation. The view here is a little different than the views expressed by parents or expert researchers, different again from the many tons of books claiming to describe first hand or second hand accounts, yet she portrays the experiences and views of such as have their faces pressed against the glass in a contextually rich and sympathetic style. As someone who has been touched by autism both personally and professionally, people so diagnosed have taught me much about what it means to be human and what I should expect to find is required of me: namely, to turn up, shut up, and listen, before helping to contribute to some practical ideas. This book has echoed many of the lessons people have sought to remind me of over the last several years. In the end, Silverman suggests that an empathic scholarship, where researchers and practitioners listen hard to those often unable to formally communicate in traditionally recognised ways, may be of use. Science informed by love: it is an enticing suggestion