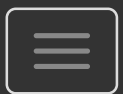


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## Physician and Patient perspectives: Autistic Spectrum Disorders

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## Abstract

This chapter presents the narratives of some people with autistic spectrum disorders (also known as autism spectrum conditions) as well as those of their families and carers. It describes the history and development of the diagnostic concept of autistic spectrum disorders and how the clinical features impact on daily life and their families. It examines the different stages through which people progress, based on their contact with services “ before diagnosis, at the time of diagnosis and their life since then. The chapter concludes with a personal account of all these stages.

## Chapter Preview

Top

## Personal Experiences Of Autism

The autistic spectrum disorders (ASDs) are classified as pervasive developmental disorders. These are conditions with an onset in early childhood and are profoundly linked to the person’s experience of life in every respect. The classical features of impairments in social communication, interaction and imagination often mark children out as different to others. For children, different is quickly termed strange, weird or odd. These children then can be subject to social exclusion, compounding the difficulties they may experience.

The clinical features of autism and related disorders are well documented, but there is no substitute for the perspective of people with these disorders and their families. There are now several novels and autobiographies written about and by people with ASDs, e.g. *The Curious Incident of the Dog in the Night-*

Time by Mark Haddon and Reflections: Me and Planet Weirdo by P. Hughes. Another book, Autism and the Myth of the Person Alone by Douglas Biklen, features heavily the words of people with ASDs.

A qualitative study of life with high-functioning autism (Hurlbutt and Chalmers, 2002) featured the experiences of three individuals as told to researchers over the course of nine months through interviews and written material. Data was analysed by coding 150 main ideas into 29 clusters then collapsing these down to seven categories. Core themes emerged which were equally supported throughout the study. The participants wished to be considered experts in the field of autism and to be consulted on issues related to autism. They are proud to have autism.

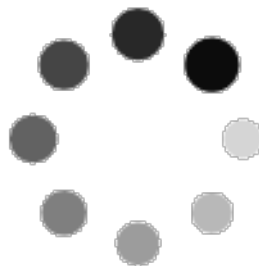
Other research has focussed on particular stages of life. Parenting a child with an ASD has come under great scrutiny. A grounded theory study (Lasser and Corley, 2008) involved 20 parents of children with Asperger's Disorder in the USA. They reported the phenomenon of constructing normalcy emerged as important for many parents. In other words, this is the struggle to establish a shared understanding of what is normal for their children. They also review some of the literature around particular challenges in parenting a child with an ASD:

- Diagnostic process
  - Waiting, loss of idealised child, relief
- Parental perceptions of uneven development
  - Advancement followed by loss of skills leading to confusion
- Channelling the child's strengths
  - Importance of identifying them and building upon them
- Ambiguity of future outcomes
  - Difficulty knowing how much support a child will need in the future

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