Chapter 4

Physician and Patient Perspectives:
Autistic Spectrum Disorders

Paul Bradley
Hertfordshire Partnership NHS Foundation Trust, UK

Peter Griffin
Teacher in Further Education, UK

Ann Griffin
Caregiver and Mother, UK

Kamalika Mukherj
Hertfordshire Partnership NHS Foundation Trust, UK

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.

INTRODUCTION

Autism is a disorder which profoundly effects how people communicate. Although it is often associated with intellectual disability and occasionally occurs as a part of other clinical syndromes, features often exist in people with average or above average intelligence. It is important that health professionals are able to recognise and understand this group, regardless of their discipline, in order to provide high quality care. Recent estimates put the prevalence as high as 1% amongst children and young people; this is explored further later in the chapter.

In recent years there has been more widespread awareness of the characteristic features leading to more appropriate support being offered. In the

past some people would have been mistreated by services believing they had a mental illness like schizophrenia. Many people would have passed undetected, forming their own coping strategies seeming to society eccentric or unusual. Whilst the diagnoses are made on the basis of deficits in some areas, there are also strengths and abilities which people are able to build on.

In this chapter we will present the narratives of some people with autistic spectrum disorders (also known as autism spectrum conditions) as well as those of their families and carers. We will see how some of the clinical features impact on people's lives and include their advice on how health professionals could support them. We will look at the different stages through which people progress, based on their contact with services – before diagnosis, at the time of diagnosis and then their life since then.

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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