


ROUTLEDGE FOCUS



UNDERSTANDING THE VOICES AND EDUCATIONAL EXPERIENCES OF AUTISTIC YOUNG PEOPLE

From Research to Practice

Craig Goodall

ROUTLEDGE
Focus



The opinions and experiences of autistic children and young people are all too often overlooked in autism research and practice. Goodall's inspiring book puts that right, by placing young people at the very centre of discussion. Goodall's deep respect for, and willingness to listen to and learn from the young autistic people in his research is exemplary. Everyone with an interest in autism should read it.

Professor Liz Pellicano, Macquarie University, Sydney, Australia

Recently, there has been an increased emphasis on developing appropriate educational responses for children and young people on the autism spectrum. However, there are relatively few books that provide in-depth insights into the lives of young people on the autism spectrum as they navigate their school journeys. Craig Goodall's book addresses this serious gap in the literature through a scholarly yet grounded piece of work. Craig has adopted a creative research approach designed to support and empower these young people. Their stories, their struggles and their successes are at the heart of this book. This is essential reading for practitioners, policymakers and all those interested in developing inclusive learning environments as we begin to learn about how the voices of these young people can be recognised and help us to reconceptualise school life so that these young people can be fully included.

Michael Shevlin, Professor in Inclusive Education, School of Education and Director of Trinity Centre for People with Intellectual Disabilities, Trinity College Dublin, Ireland

This is a highly important and insightful book on the educational experiences of a group of young people who have, for too long, been rendered invisible by dominant educational pedagogy. In this key text for educators, trainee teachers, researchers and policymakers, Goodall exposes us to the rich possibilities and practicalities of participatory and rights-based research in accessing autistic young people's perspectives. The findings force us as researchers and educators to engage critically with inclusive education discourse and its emergent tensions, not least the implications for policy and practice. These voices cannot and should not be ignored.

Dr Bronagh Byrne, Lecturer in Social Policy, Programme Director for MSc Children's Rights, School of Social Sciences, Education and Social Work, Queen's University, Belfast, Northern Ireland



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Understanding the Voices and Educational Experiences of Autistic Young People

Providing a ‘one stop’ text, *Understanding the Voices and Educational Experiences of Autistic Young People* is a unique and comprehensive contribution to bridge the gap between theory, research and practice. Based on the author’s teaching and research experience, this book provides a theoretical and practical framework for participatory rights-based autism research and demonstrates the benefits of – and growing emphasis on – voice and participation research; if done correctly it can be of immense benefit to policy, practice and how we support autistic young people.

Alongside a critical and extensive review of research literature and debate on the efficacy of mainstream inclusion for autistic children, the book provides practical advice on how to support autistic children in research and in school. Significantly, Goodall investigates and presents the educational experiences of autistic young people – including girls – and their suggestions to improve educational practice from their own perspectives, as opposed to adult stakeholders.

This book will act as a key text for student teachers, practitioner-researchers, those already supporting autistic children in education or social settings (including teachers, school leaders, special education leads, policymakers) and academics researching in the areas of autism and inclusion.

Dr Craig Goodall is an educator with 12 years’ experience working with autistic young people and others out of mainstream education in Northern Ireland, UK.

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Understanding the Voices and Educational Experiences of Autistic Young People

From Research to Practice

Craig Goodall

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Preface

I have taught in an Alternative Education Provision (AEP) in Northern Ireland since 2007. From discussions with autistic young people I became aware that their mainstream educational experiences had, in the main, been negative, resulting in a refusal to attend school – anxiety based for many – and, for some, their behaviour was deemed too challenging for mainstream to support, resulting in exclusion. Bullying, anxiety, fear of the unknown, teachers who lacked understanding and a lack of flexibility have all been informally discussed by these young people. Outside school I began working with parents and learned that many of their autistic children have had similar experiences, resulting in some having to be withdrawn from formal education. This added to the picture that mainstream school may not be the most appropriate environment in which to meet the needs of all academically able autistic young people. Research conducted for my autism Master's degree indicated that teachers want and need more autism-specific training, but that the attitudes held are not always conducive to wanting to understand and engender inclusion.

In addition, my interest in children's rights, rights-based approaches and participatory autism research grew throughout my modules on the Doctorate of Education programme. I also explored the effectiveness of mainstream inclusion for autistic children and theories for developing inclusive practice. It became apparent that few studies have directly explored the educational experiences of autistic young people and their experiences of, and thoughts on, inclusion. Such a dearth of research means that there is very little rights-based qualitative participatory research exploring the perspectives of autistic young people themselves. Studies that do investigate these experiences generally do so through the lens of teachers or parents – the adults.

As a result, my resolve to afford autistic young people their right to be heard and participate in matters that impact on their lives (including

research) from an approach that is not only rights respecting but rights enabling was strengthened. I judged that it was time to garner the educational experiences of these children and hopefully to use these insider narratives to inform policy and practice.

The school environment can be a hostile place for those who process the world differently. Thus, the educational experiences of these young people ought to be sought and used to inform school policy and practice, and gain deeper insight into mainstream inclusion for autistic learners.

In this book I not only present the experiences of these autistic young people but will guide readers through my Doctoral research, providing simple strategies and exploring decisions I made. Some of the issues I considered and overcame were guided by my experience working with many autistic young people and are not readily evident within research or educational texts. These methodological considerations will be assessed within a comprehensive discussion of extant literature relating to inclusion, rights, education and autism. A unique contribution to the field, this book – which will be of interest to educators (including trainee teachers and practitioner-researchers), undergraduate and postgraduate researchers, academics in education and psychology, educational policy-makers, parents and autistic people themselves – will bridge the gaps between theory, research and practice. The book, structured across nine chapters, makes a valuable and comprehensive contribution to the field.

1 Setting the scene

Introduction

Autistic Spectrum Disorder (ASD) is described as the most prevalent of all neurodevelopmental disorders (Jang et al., 2014). ASD is formally characterised by a shared dyad of interacting challenges in social communication and repetitive behaviours, including difficulties (or differences) interacting with others and making sense of the social and sensory world. Although shared, this dyad is experienced differently by each individual and the term autism, a single word, attempts to encapsulate the experiences, characteristics and lives of many. By involving autistic young people in research, we will better understand their experiences of education and hopefully effect change in policy and practice.

This book bridges the gap between theory (the inclusion debate), research (understanding and supporting the voices of autistic young people) and practice (educational experience, school improvement and inclusion from the perspectives of autistic young people). I use this opening chapter to set the scene for what lies ahead. I explore historical perspectives on autism, how perceptions of autism are changing and the impact of the terminology we use for supporting autistic young people in education and research. As I will argue in this book, a lack of understanding, acceptance, support and unfriendly (school) environments exacerbate these challenges.

Historical perspectives

During the Second World War Leo Kanner (1943) studied 11 children of normal physical development and was the first to identify a definition for autism. According to him, the main features of this condition include severe social impairment, delayed speech development, impairments in communication, rigid thought processes and ritualistic patterns of

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behaviour. Kanner diagnosed these children as having ‘Infantile Autism’, or ‘Kanner Syndrome’. In his classic paper ‘*Autistic Disturbance of Affect Contact*’, Kanner (1943, p.250) describes the children he studied as having ‘come into the world with innate inability to form the usual, biologically provided affective contact with people’. This description would now be considered offensive, inaccurate and demeaning for many autistic people and their allies.

Hans Asperger (1944), also during the Second World War, worked with a similar group of children and identified a cluster that had social difficulties. However, in comparison to Kanner’s group these children had average cognitive ability and displayed good verbal skills. These children are described as having ‘Asperger Syndrome’ (AS), a phrase first used by Wing (1981) and a condition Asperger himself is now considered to have had (Le Blanc and Volkers, 2008). Wing (1996) suggests that those with AS are sometimes known as having ‘High Functioning Autism’ – a divisive descriptor, as discussed below.

The work of Wing and Gould (1979) developed the concept that Kanner Syndrome, or autism, and AS could be part of a wider spectrum of disorders known as Autistic Spectrum Disorders. However, the concept of a spectrum is perhaps too linear and an over-simplistic representation of the diverse, changing nature and experiences of autistic people. The challenges faced can change from one situation to the next based on a multitude of social, sensory and environmental factors. The ‘spectrum’ can create the assumption of an undeviating scale ranging from a ‘little autistic’ to ‘very autistic’, thus pigeonholing autistic people into discrete, unchanging groups based on apparent, assumed static, levels of functioning; the low end and the high end of the spectrum – this is wonderfully illustrated by Rebecca Burgess (2016, www.rebecca-burgess.co.uk). Caroline Hearst proposed a constellation model to represent the spiky, non-linear profiles and experiences of autistic people, which I also find useful (see www.autangel.org.uk/autism-constellation.html). I like to use a kaleidoscope analogy to represent the vast diversity and non-constant changing nature of autism for the individual. The importance of terminology and perception is revisited later.

Prevalence

Prevalence rates vary across countries and depend on diagnostic services, awareness amongst professionals and, ultimately, resources. The Department of Health, Social Services and Public Safety (2019) in Northern Ireland indicates that, in 2018/19, 3.3% of the school-aged population are autistic, an increase from 1.2% in 2008/09. This increase

could be attributed to greater awareness amongst a range of professionals working with young people, such as teachers, an increase in diagnostic services and earlier identification. Wing (1997) suggests other possible reasons, such as an actual increase in the number of cases and a rise in other co-occurring disorders (with autism still being seen as a spectrum condition). Martin (2012) adds an increase in openness to seek a diagnosis in light of decreased social stigma attached to this list of reasons. To summarise, prevalence estimates have increased over time; this most likely represents changes in the concepts, definitions, service availability and awareness of autistic-spectrum disorders in both the lay and professional public.

Gender ratio and bias

Kreiser and White (2014) report a (relatively) consistent male bias of 4:1, although ratios vary across the spectrum, ranging from 2:1 in those with intellectual disabilities to 5.1:1 in those without (Kim et al., 2011). The DHSSPSNI (2019) indicates a ratio of 3.4:1, or 1.5% of females compared to 5.1% of males within the school-age population of Northern Ireland, although, according to Cooper, Smith and Russel (2018), a large proportion of autistic people do not align to the male/female binary position on gender, which makes determining gender ratios more difficult.

Autism is potentially under-identified in females without co-occurring learning difficulties. This may be due to subtle gender differences in the characteristics of autistic females compared to males, such as less unusual stereotyped and repetitive behaviours – or such behaviours being masked or camouflaged – coupled with a lack of autistic female research (Goodall and MacKenzie, 2018). Fletcher-Watson and Happé (2019, pp.42–43) also outline diagnostic overshadowing for females. They suggest:

if clinicians don't think 'autism' when they meet a girl with social difficulties, they may think social anxiety, eating disorder or depression: diagnostic overshadowing occurs when clinicians stop at one presenting problem and don't go on to consider, for example, eating disorder *and* autism.

Professionals rely on observations and subjective judgements when deciding to make a diagnosis. Together these factors, arguably, give rise to gender bias in the diagnostic criteria used, which is difficult to uncover. Lai et al. (2015) propose that, in comparison to autistic males, females have better expressive behaviours, such as holding reciprocal

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conversations, and better initiation of interactions, but poorer maintenance of these. Irrespective of the estimated ratios reported, literature suggests that ASD is predominantly diagnosed in males, with females being less likely to receive a diagnosis than males displaying similar levels of autistic traits (Baldwin and Costley, 2016). This, as I discuss in Chapter Five, means fewer autistic females are involved in research, 'leading to a vicious cycle of ignorance about possible gender differences' (Fletcher-Watson and Happé, 2019, p.42).

I refer to female autistic research at various points within this book and present the vivid lived experiences of two autistic teenage girls alongside boys in Chapters Six to Eight in order to add to the limited body of research concerning females. Several recent texts focus primarily on autistic females and issues such as camouflaging and diagnosis (for example, Carpenter, Happé and Egerton, 2019).

Aetiology

In the 1960s Bettelheim (1967) facilitated the then widespread theory that autism originated from specific parenting styles, a belief subscribed to by Kanner, who is described as the main proponent of 'refrigerator mothers' (Strathearn, 2009). Jordan (1999, p.50) describes Kanner's belief that the 'mild autistic features of detachment and social difficulty that he saw in the parents of the children he treated could account for autism in their children'. Based on his own personal experiences, Bettelheim (1967) made the comparison between autistic children and those who suffered in the unloving and threatening conditions within Nazi concentration camps. It was thought the child developed autism as a result of a lack of warmth from parents, particularly mothers. From the 1970s, rejection of the theory of 'refrigerator mothering' grew as scientific research began uncovering a neurobiological basis for autism (Bernier and Gerdts, 2010). Prominent psychiatrists such as Sir Michael Rutter and Dr Susan Folstein (Folstein and Rutter, 1977) studied same-sexed twins (11 monozygotic and 10 dizygotic pairs) and concluded that autism is a genetically based disorder and not caused by poor parenting, or 'refrigerator mothering'. There has never been any scientific evidence that autism is caused by poor parenting.

The expanding body of genetic research has, and continues to, unveil the complexity of autism with multiple contributing genes. There are, as yet, no biological features providing a distinctive marker, or cause, of autism (Muhle et al., 2018). Importantly, there are no causal links between MMR vaccinations and autism, as purported by Dr Andrew Wakefield in 1998. This has been vehemently rejected (for instance, see