

# Clinical Topics in Disorders of Intellectual Development

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978-1-909-72639-0 — Clinical Topics in Disorders of Intellectual Development  
Edited by Marc Woodbury-Smith  
Frontmatter  
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To Kara, Charlotte and Marguerite

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RCPsych Publications

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# Contents

|   |     |
|---|-----|
| List of contributors  | vii |
| Foreword  | ix  |
| Preface   | xi  |
| <b>Part 1: Disorders of intellectual development: concept and epidemiology</b>  |     |
| 1 Disorders of intellectual development: historical, conceptual, epidemiological and nosological overview<br><i>Anthony Holland</i> | 3   |
| 2 Behavioural phenotypes<br><i>Jeremy Turk</i>  | 22  |
| <b>Part 2: Disorders of intellectual development: comorbidity and complications</b>   |     |
| 3 Psychiatric illness and disorders of intellectual development: a dual diagnosis<br><i>Marc Woodbury-Smith and Sheila Hollins</i>  | 41  |
| 4 Anxiety disorders<br><i>Sherva Elizabeth Cooray, Alina Bakala and Anusha Wijeratne</i>  | 58  |
| 5 Behaviour problems<br><i>Elsbeth Bradley and Marika Korossy</i>   | 72  |
| 6 Epilepsy<br><i>Marc Woodbury-Smith and Howard Ring</i>  | 113 |
| 7 The use of psychotropic medications to manage problem behaviours in adults<br><i>Shoumitro Deb</i>                                | 130 |
| <b>Part 3: Autism spectrum disorder</b>   |     |
| 8 Overview of autism spectrum disorder<br><i>Stelios Georgiades, Terry Bennett and Peter Szatmari</i>                               | 147 |

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 CONTENTS
 

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|                                  |  |     |
|----------------------------------|--|-----|
| 9                                | Autism spectrum disorder and Asperger syndrome<br><i>Tom Berney</i>  | 159 |
| 10                               | Pharmacological management of core and comorbid symptoms<br>in autism spectrum disorder<br><i>Rachel Elvins and Jonathan Green</i>                       | 178 |
| 11                               | Psychological treatment of autism spectrum disorder<br><i>Jo-Ann Reitzel, Jane Summers and Irene Drmic</i>   | 201 |
| <b>Part 4: Service provision</b> |  |     |
| 12                               | Improving the general health of people with disorders of<br>intellectual development<br><i>Mike Kerr and Penny Blake</i>                                 | 239 |
| 13                               | Bridging the gap: linking primary and secondary care for people<br>with disorders of intellectual development<br><i>Neill J. Simpson and Neil Arnott</i> | 249 |
| 14                               | Ageing in people with disorders of intellectual development<br><i>Gregory O'Brien and Paul White</i>   | 264 |
| 15                               | Services for children with disorders of intellectual development<br>and mental health needs<br><i>Asif Zia and Anagha Sardesai</i>                       | 277 |
| 16                               | Forensic psychiatry for people with disorders of intellectual<br>development: a personal reflection<br><i>Simon Martin Halstead</i>                      | 291 |
|                                  | Index  | 305 |

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# Foreword

Fred R. Volkmar

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Awareness of children with significant problems in intellectual development can be traced to antiquity but awareness of associated problems in mental health is a much more recent phenomenon. The increase in awareness in recent years can be related to several factors: greater inclusion of individuals with disabilities in the population, the need to support individuals of all ages in their communities, and increasing sophistication on the part of both researchers and clinicians. Sadly, and somewhat paradoxically, a diagnosis of intellectual disability in the more distant past often led to a presumption that such individuals were somehow protected from other problems – the phenomenon known as ‘diagnostic overshadowing’. However, research with this population began to suggest that rather the converse was true, with persons exhibiting milder intellectual disability having 4- to 5-fold increases in rates of associated psychiatric problems (Reiss & Szyszko, 1983). Awareness also began to increase regarding the difficulty of applying the usual models of psychiatric nosology, particularly in individuals with more severe intellectual disability (Fletcher *et al*, 2007). Other work began to note significant associations between certain syndromic forms of intellectual disability and specific mental disorders (Dykens & Hodapp, 2001). This volume provides an important overview and update of the current status of the field, and areas where more work is needed.

The opening chapters of this book provide a very helpful overview of basic issues and approaches to classifying intellectual disability and characterising behavioural phenotypes. The next section summarises comorbidity, with specific chapters on commonly associated conditions in general, and anxiety disorders in particular. Relevant disorders are highlighted including behavioural difficulties, problems associated with seizure disorders, and pharmacological management.

Part three of the volume focuses on autism and related conditions. This is an area where there has been a vast increase in research, although, unfortunately, problems in adolescents and adults have been much less frequently addressed. Chapter 8 provides a helpful overview, with other chapters focused more specifically on Asperger syndrome and on pharmacological management. Chapter 11 on behavioral and psychological

## FOREWORD

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approaches to management is an excellent addition to the literature on this topic.

The next section of the volume is concerned with service provision. Chapters address more general health care needs as well as the important gap in linking primary and secondary care. The issue of ageing in this population is relatively infrequently addressed, and Chapter 14 provides an extremely timely summary. The final chapters address issues of services and mental health needs for children as well as forensic issues.

This book represents the current state-of-the-art in addressing issues of concern to all of us who work with individuals with intellectual disability. It will be of great value to both clinicians and researchers and will be a resource for years to come.

Dykens EM, Hodapp RM (2001) Research in mental retardation: toward an etiologic approach. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **42**: 49–71.

Fletcher RJ, Loschen E, Stavrakaki C, et al (eds) (2007) *Diagnostic Manual – Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability*. NADD Press.

Reiss S, Szyszko J (1983) Diagnostic overshadowing and professional experience with mentally retarded persons. *American Journal of Mental Deficiency*, **87**: 396–402.

## Preface

The practice of medicine has seen significant changes in recent years, the result of scientific advances in diagnosis and treatment, as well as more general changes in the pattern of disease in our ever-expanding population. Psychiatry itself has undergone more fundamental changes, due in part to recent modifications in classification (DSM-5, and forthcoming in ICD-11) and greater clinical subspecialisation. Moreover, for a variety of reasons comprising both well-elucidated factors and those that are poorly understood, the prevalence of mental disorders continues to rise, which has major implications for the healthcare budget of the nation.

My own specialty, the psychiatry of intellectual disabilities, has itself seen innumerable changes. It has risen in status from psychiatry's Cinderella subspecialty to one that embraces new technologies and scientific advances, in addition to benefitting from new legislation. This is acutely visible in relation to the care of individuals with autism spectrum disorder (ASD), which represents a significant component of the clinical workload of healthcare professionals in the psychiatry of intellectual disabilities. Advances in ASD's conceptualisation, diagnosis, comorbidity and treatment are increasingly incorporated into clinical practice, which includes the publication of evidenced-based guidelines. Generally speaking, the psychiatry of intellectual disabilities sits neatly on the interface of child and adolescent psychiatry, neurology and genetics, and, as a matter of course, it will be affected by developments in these specialisms.

Consequently, while we find ourselves at an exciting juncture in the care of the population of those with disorders of intellectual development (DID), a large body of literature exists that could impact on the clinical care we provide. By 'we' I do not refer principally to psychiatrists, but instead to all health and social care professionals working with this population. I believe that both clinicians and allied healthcare workers can benefit from research evidence being distilled down to the most important, clinically relevant points. Both can also profit from the availability of up-to-date references, as they provide the opportunity for broader and deeper reading, and it is with this in mind that the current volume was prepared.

Several of the chapters herein are revised and updated versions of previously published articles from *Advances in Psychiatric Treatment*. Many

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PREFACE

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chapters, however, have been commissioned specifically for this book. The emphasis throughout is on clinical care, and the most common presenting complaints and their diagnosis and management. Particular chapters, such as those by Tony Holland (Chapter 1) and Jeremy Turk (Chapter 2), facilitate a wider, conceptual understanding, whereas Simon Halstead's personal perspective looks beyond the forensic care of this population to articulate a growing awareness of the potential problems, ethical and otherwise, of definitional changes, and service provision for the DID population (Chapter 16). Even if his polemics are at odds with the reader's own viewpoint, there is no doubt that he raises important points that cannot be ignored, as they are fundamental to the future of caring for the DID population.

A chapter specifically focusing on Asperger syndrome is also included (Chapter 9). Despite its removal from the DSM-5, there is little doubt that this term remains clinically relevant, and will continue to be for the foreseeable future. This chapter also provides a more in-depth discussion of the characteristics of adults with higher functioning ASD, along with their mental health comorbidities. Further, in view of the importance of ASD, additional chapters provide a detailed overview of ASD (Chapter 8), and a presentation of pharmacological (Chapter 10) and psychological (Chapter 11) management.

With a particular focus on clinical care, the two broad areas of (i) comorbidity and complications of DID (Part 2 and chapters therein) and, (ii) service provision (Part 4 and chapters therein) are discussed in detail. Again, detailed exposition is given to those key areas that have most clinical valence. As such, the epidemiology, aetiology and management of psychiatric disorders are discussed (Chapter 3), along with a more detailed consideration of anxiety disorders (Chapter 4) and behaviour problems (Chapter 5). Responsibility for the diagnosis and management of epilepsy often falls to the psychiatrist; however, even if this is not the case, the neuropsychiatric complications of epilepsy are an important aspect of clinical care (Chapter 6). Finally, the use of psychotropic medications in this population for problem behaviours is considered, drawing on the recommendations from recently published national and international guidelines (Chapter 7).

Service provision focuses on several key areas, which comprise general health needs (Chapter 12), and models of primary and specialist care (Chapter 13). In addition, other chapters focus more specifically on the service needs of the ageing population with DID (Chapter 14), of children (Chapter 15), and of the interface with the criminal justice system and specialist forensic services (Chapter 16).

Of course, a single volume such as this cannot cover everything; consequently, certain areas such as legislation, education and vocational needs are not specifically included. Nor was I able to incorporate the perspectives of nursing, social work, or occupational, speech and physical therapies. This in no way reflects any judgement of perceived importance, but is merely the result of space limitation.

The reader will note that the term Disorders of Intellectual Development (DID) is used throughout. This is the term that, after much debate, was decided on by WHO for the forthcoming 11th revision of the International Classification of Diseases (ICD-11, due for publication in 2017). Clearly, terminology has not only changed over time, but also between the two principal classification systems, with the DSM-5 including the term ‘intellectual developmental disorder’ defined in almost identical terms (see Chapter 1 for further discussion). It is important to bear in mind these different terminologies and their relationship as discussed by Holland (Chapter 1).

During my own tenure as a clinician working with this population, I have been fortunate to have worked directly with key leaders such as Tony Holland, Peter Szatmari, Fred Volkmar and Greg O’Brien. I first met Greg in the early 2000s through our respective roles in the Society for the Study of Behavioural Phenotypes (SSBP), and I later worked more closely with him, albeit for a short time, as a colleague in Northumberland. He went on to become my College mentor until I left the UK in 2007, but I did keep in touch with him. Greg made enormous contributions to the field of developmental psychiatry as evidenced by his widely cited publications, and was well regarded and respected, both as a clinician and friend and colleague, by all those who worked with him before his death in 2014. I am deeply honoured to have known him, and for him to have contributed to this book.

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