

# Psychiatric and Behavioral Disorders in Intellectual and Developmental Disabilities

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**Third Edition**

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**Third Edition**

Edited by

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## Preface

This is the third edition of *Psychiatric and Behavioral Disorders in Intellectual and Developmental Disabilities*. It is the update of a book that was first published in 1999 (Bouras, 1999), with the second edition published in 2007 (Bouras and Holt, 2007), and it has become widely known and highly regarded in this field. Like the earlier editions, this new edition is primarily focused on intellectual disabilities (ID), as defined by the standard classification systems, but also includes content on other developmental disabilities. It focuses clearly on mental health aspects of ID rather than on broader health issues, but the focus is on mental ill-health in its widest sense to include significant behavioral problems. It provides the essential concepts and facts for all those involved in the mental health care of people with ID. It brings together the research findings and includes concise chapters on all of the key topics by a multiprofessional team of contributors. The international authors provide arguably the most worldwide perspective of the research in the mental health of ID field. In reviewing each area, the authors have included advances since the last edition and many have offered pointers to further progress. In addition, this book also provides useful principles for clinical practice including those underpinning assessment, management, and service delivery and is a comprehensive resource on which these can be based.

The book is divided into sections including *foundations*, *mental disorders*, *interventions*, *special topics*, and *services*. The *foundations* section is essential reading for the basic concepts of this field. Firstly, the context is always needed to make best sense of the current situation and evidence. Nick Bouras has been one of the leading influences in the study and practice of the mental health aspects of ID. He contributes the chapter on *historical and international perspectives*, which sets out the context of where the field is now, well into the 21st century. Understanding the key concepts that underpin clinical practice is vital for clinicians and researchers, and managers of services for people with ID, in order to maintain the clear focus of what is needed amidst all the competing demands and agendas. Of key importance is the current position of deinstitutionalization in most high-income countries, driven at least in part by the normalization philosophy. It is by now well known that for a large period of history mental health problems were not considered in people with ID. It is also well known now that, converse to many expectations, the prevalence of mental health and behavioral problems was not decreased by deinstitutionalization in the latter part of the 20th century. Lessons can, thus, be drawn from history for those countries still yet to undergo the deinstitutionalization process. For example, this chapter highlights how in the UK, the development of the “community learning disabilities teams” were not as radical as they perhaps may have seemed to be. These new teams, in many ways, recreated the workings of the mental asylums by being set up as a “one-stop shop.” Although seemingly comprehensive on one hand, on the other they led to some blurring of focus in an attempt to meet all the various needs of people with ID. In particular this contributed towards a disconnection with generic mental health services, meaning that people with mental health problems often fall in the gaps between services. The chapter helps to show the inevitably temporal nature of service design and the trends in this field, for example, the relatively recent increased recognition and emphasis on autism spectrum disorders.

The extended chapter in two parts by Marco O. Bertelli, Luis Salvador-Carulla, and James Harris on (i) *classification* and (ii) *diagnosis* of ID provides the core to which all the other chapters are related. They describe the process of moving from ICD-10 and DSM-IV conceptualizations to ICD-11 (unpublished at the time this book goes to print) and DSM-5. The place of ID in standard classification systems is crucial, not least to determine the relationship and connectedness of this specialist field with “mainstream” mental health. Although modified classification systems have been and are useful for advancing understanding of the atypical presentations seen in people with less than typical IQ, it is notable that they have not been adopted uniformly. The authors describe how the terminology between Intellectual Developmental Disorder (IDD) and ID in DSM-5 was developed and describe how the previously labeled *mental retardation* was simultaneously conceptualized as both a disability and a health (mental) disorder. Of note too is the relative shift in emphasis in the new DSM-5 from impairments in intellectual functioning to those in social functioning for the diagnosis of ID/IDD. Also highlighted is the recognition that the emphasis on the global IQ score is misleading owing to the large variations in specific functioning between people often found at a particular overall IQ score.

In his chapter on *epidemiology*, Jason Buckles writes a comprehensive review of the epidemiological evidence in recent years. The longstanding problems in agreeing criteria for definition and classification have been well documented. Even what should and what should not be included as a psychiatric disorder is not yet consistently agreed upon. The problems of both underdiagnosing and overdiagnosing in people with ID is highlighted, including the non-clinical influences on the diagnostic process. However, despite this, we are now further forward, allowing comparisons to be made between studies with more credibility. The author systematically examines each point in the process of epidemiological research and describes ways to progress still further despite all the difficulties. Also intimately related to these preceding chapters is the *assessment instruments and rating scales* chapter by Heidi Hermans. This includes guidance on selecting the most suitable rating instrument and includes some recent developments focusing on empowerment and digitalization.

The next section of the book contains chapters on the major types of *mental disorders*. First, Jennifer Torr reviews the *dementias* in people with ID. This topic is of continually growing importance as more and more people with ID live longer lives owing to improved treatments and living standards. Rory Sheehan, Lucy Fodor-Wynne, and Angela Hassiotis contribute the chapter on the *schizophrenia spectrum disorders*. The authors have included a review of more recent findings, helping to understand better the nature of the link between ID and the schizophrenias. The chapter on *mood disorders* by Anna M. Palucka, Pushpal Desarkar, and Yona Lunskey describes how in more recent years more is known about the links between the affective disorders and suicide and traumatic events. Jane McCarthy and Eddie Chaplin in their chapter describe the *anxiety disorders* and highlight some of the recent evidence exploring the risk factors for these, including autism, physical health problems, social exclusion, and negative life events. Again, more evidence has been forthcoming in recent years of the many genetic links with anxiety disorders.

In a very welcome new addition for this edition, Philip Dodd and Fionnuala Kelly have written a chapter on *stress, traumatic, and bereavement reactions*, which are well recognized to be of major clinical importance by all working with people with ID, and

yet not always or easily captured in standard classification systems. This chapter links the developments in stress and trauma in people with ID, including post-traumatic stress disorder and bereavement reactions. It clarifies recent terminologies used with research in the ID and the non-ID populations. William R. Lindsay and Regi Alexander next review *personality disorders* in ID. More recent evidence has looked at the prevalence of personality disorder and associated risks in forensic populations and also investigated the use of dialectical behavior therapy for people with ID.

In another important new chapter addition for this new edition of the book, Trine L. Bakken, Sissel B. Helvershou, Siv Helene Høidal, and Harald Martinsen consider the complex topic of *mental illness in people with ID and autism spectrum disorders*. Much of the recent research on the confounding between autism and mental illness that can occur and the identification of psychopathology in autism has been done by the authors themselves. The chapter by Elizabeth Evans and Julian Trollor on *ADHD in people with ID* includes a review of evidence regarding the family and educational interventions that are crucial in the management of ADHD in ID. The authors also include various guidelines that have been published by leading authorities since the last edition of this book.

The section on *interventions* contains four chapters. The chapter by Stephen Ruedrich on *psychopharmacology* includes a review of research into medication use for behavioral problems, in genetic syndromes, and for autism spectrum disorders. It will be directly useful for clinical practice, drawing on recent medication guidelines. The following chapters then include reviews of the modifications and use to date of *psychodynamic psychotherapy* (Nigel Beail) and *cognitive-behavioral therapy* (Dave Dagnan). This clinical use of the psychotherapies, and the tentatively positive research findings so far, continue to slowly confound some previously pessimistic views that these psychotherapies could not be modified to be made applicable for people with ID. These chapters show that a key to progress is publication of evidence, to include case studies where larger-scale studies are not yet possible or feasible, and also to publish reflections on clinical practice. Betsey A. Benson then contributes the chapter on *behavioral approaches*. Evidence has grown of effective behavioral treatments for people with ID, with multiple new studies since the last edition. However, there remain many stumbling blocks between the research findings and the translation of them into practice, and one of the most important of these seems to be in staff training.

The *special topics* section chapter on the *psychopathology of children with ID* by Bruce Tonge will be of particular interest to clinicians in child and adolescent services, as it includes several case studies and evidence-based guidance on clinical assessment. The chapter on *behavioral phenotypes/genetic syndromes* by Robert M. Hodapp, Nathan A. Dankner, and Elisabeth M. Dykens is of great interest because there has been so much recent advancement in the field of genetics. The authors highlight that findings are becoming more nuanced, for example regarding subsets of people with specific conditions or to phenotypic variants caused by quite closely related genetic changes.

In the next chapter John Taylor and William R. Lindsay review *offending behavior* in people with ID. In this chapter they include recent evidence showing that risk assessment instruments used and evaluated in the non-ID population can also be used with similar accuracy with offenders with ID. They also include recent research on psychological interventions, both individual and group-based, for the reduction of anger and aggression in offenders with ID. Sally-Ann Cooper writes the chapter on *problem behaviors and*

*the interface with psychiatric disorders.* The author reviews some of the statistical analyses, including factor analyses, which have been employed to look at the relationships between mental health problems and problem behaviors. The chapter on *the interface between medical and psychiatric disorders* is authored by Jessica A. Hellings and Seema Jain. The comorbidity, service need, and assessment problems from this interface described by the authors are of crucial importance for assessment and treatment of psychiatric and behavioral disorders in people with ID. In the chapter on *epilepsy*, Frank M.C. Besag reviews the relationship between epilepsy and ID, and then the complicated triad between epilepsy, ID, and mental health problems. Recent evidence on the associations with specific chromosomal abnormalities and epilepsy and ID are included.

In the section on *services*, Johanna Lake, Carly McMorris, and Yona Lunskey have written the chapter on *specialist and mainstream mental health services* for people with ID. They summarize what has been learnt about the outcomes of people using these services and consider the main models of service delivery. They highlight the emerging literature recently regarding hybrid service configurations. The following two new addition chapters highlight the importance of clinicians remembering who the services are really for. People with ID and their carers and families are increasingly acknowledged to have the right to a major say in the services they receive. Many of the research studies reported in these next two chapters have, thus, been completed since the last edition of this book. Katrina Scior has written a new addition chapter on *service users' and carers' experiences of mental health services*, which includes evidence that has emerged regarding the importance of staff attitudes for the experiences of people with ID receiving mental health services. Gemma L. Unwin, Shoumitro Deb, and John Rose contribute with another new addition chapter on *carer and family perspectives*. Research findings on positive aspects of caring are included as well as the evidence on the risk of carer stress and burnout.

Finally, there is a *reflections* chapter by Colin Hemmings, which considers all of the preceding chapters in this book as a whole and reflects on some of the ongoing debates and trends in this field. It outlines some of the ways the field could develop, including in services and research, towards the time when a further edition of this book will be necessary.

## References

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