# Introduction

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There is a growing recognition over the last 25 years that adults with intellectual disability (ID) are vulnerable to mental health problems due to particular biological, psychological and social factors. In this handbook we aimed to provide a comprehensive and up-to-date overview of research and critically evaluate the complexities in both aetiology and manifestation of psychopathology in those with ID. We also review assessment, interventions and service issues with an emphasis on translating research evidence into clinical practice and policy. The aim was to provide a reflection of current practice and research as well as implications for future clinical practice and service delivery. The handbook is written primarily for doctoral level professionals and doctoral level students in training across a range of disciplines such as psychology, psychiatry, special education, communication disorders, child development and social work.

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### **Content and Structure**

The first section of this handbook covers general conceptual issues as well as assessment approaches of psychopathology providing a review of diagnostic trends and clinical dilemmas that mental health practitioners face when working with adults with ID and comorbid psychopathology. Key legislations, policies and scientific understanding of ID have evolved over time. Chapter 2 provides an overview of the history of ID as well as factors that determine epidemiology (Maulik, Harbour, & McCarthy, 2013). Chapter 3 outlines principles of clinical assessments with reference to specific mental health disorders, challenging behaviour and psychological treatments (Alim, Paschos, & Herne, 2013). Advantages and disadvantages of using structured assessments in clinical practice are being discussed in Chap. 4. A selection of assessments is compared in relation to their psychometric properties but also according to different models of assessments and staff skills (Moss & Hurley, 2013). Assessment issues are also discussed in Chap. 5 with respect to modern diagnostic criteria, leading operational definitions and models of psychopathology understanding (Hamelin, Maum, & Sturmey, 2013).

The second section of this book focuses on key aetiological issues. Neuroimaging has been successfully used to investigate in vivo brain anatomy and functioning. Chapter 6 provides an introduction to neuroimaging technologies 1

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investigating brain structure, functioning and brain chemistry with emphasis on mental healthrelated technological applications as well as neurological conditions commonly associated with ID (Ecker, 2013). Particular neurological conditions such as epilepsy are far from uncommon in adults with ID and can shed light on underlying mechanisms of atypical neurodevelopment. Patients with epilepsy and ID are at increased risk of developing additional cognitive dysfunction and psychiatric disorder. Chapter 7 reviews the complex interactions between mental health, neurocognition and epilepsy in people with ID and discusses clinical implications for the development of appropriate care management plans (Winterhalder & Ring, 2013).

Chapter 8 is comprehensive review of behavioural phenotypes and genetic syndromes. The idea that certain ID syndromes are associated with distinctive physical, behavioural and cognitive characteristics is not new. Nevertheless the genetic advances over the last decades have resulted not only in increased understanding of the aetiology but also phenotypic description of behaviour, and mental disorder has become more possible with technologically advanced tools. The great challenge for the years to come will be to translate understanding of the genetics of ID into understanding of the mechanisms underlying impaired cognition, behavioural and emotional disturbance, as well as to develop new targets for treatment (Paschos, Bass, & Strydom, 2013).

Any attempt to understand aetiology factors in psychopathology without a critical understanding of psychosocial issues surrounding the emotional and behavioural difficulties in adults with ID would be inevitably incomplete. Chapter 9 provides a critical review of psychological and social factors (including gender, level of functioning, ethnicity, life adversities, early family relationships etc.) that are likely to be implicated in the onset and maintenance of comorbid conditions. Bridging psychosocial and behavioural genetics research is the obvious future challenge. Psychosocial risk factors need to be better understood, as do protective factors such as secure attachments, supportive relationships achievements, social support and community participation (Magiati, Tsakanikos, & Howlin, 2013).

The third section of this handbook explores aspects of comorbid psychopathology in adults with ID along with related clinical and diagnostic issues. Chapter 10 discusses clinical presentation and management of schizophrenia in people with ID. Although Schizophrenia Spectrum Disorders are generally thought to be more difficult to detect and diagnose in adults with ID than in the general population; the estimated prevalence rate of these disorders is 3 times higher than the in general population (Hemmings, 2013). Chapter 10 presents common mental disorders (depressive and anxiety disorders, Obsessive Compulsive Disorder and Post Traumatic Stress Disorder) often seen in adults with ID. The prevalence of these disorders is similar if not higher than in the general population; however, diagnosis can be complicated by atypical presentation of symptoms. This chapter also describes the epidemiology, aetiology, classification and current guidance on management for common mental disorders in adults with ID (Hassiotis, Stueber, Thomas, & Charlot, 2013).

Chapter 12 explores the concept of personality disorder in relation to challenging behaviour and mental health and reflects on the usefulness of this diagnosis for people with ID. The boundaries between mental health, challenging behaviour and personality disorder are explored in an attempt to enhance understanding of the clinical value but also the limitations of this diagnostic category. The clinical outcomes for those with ID and personality disorder remain unclear especially in those with severe personality disorders (Flynn, 2013).

Significant improvements in health and social care has led to dramatic increase in the life expectancy of people with ID and a subsequent increase in age related conditions, including dementia. Chapter 13 discusses the causes and features of dementia in people with ID, as well as additional considerations that need to be taken in account when assessing and managing dementia in this particular patient group (Strydom & Sinai, 2013).

Chapter 14 deals with the issue of substance abuse in adults with ID, a particular underresearched area. When deinstitutionalisation started almost 40 years ago, policy makers and mental health practitioners were perhaps not ready to predict the issues that would be faced by people with ID given free access to and opportunity within society. This chapter examines the phenomenon of substance abuse in people with ID, considering legal, illicit and prescribed substances. Issues of prevalence and psychopathology are addressed along with biological, psychological and social factors frequently associated with substance use, and future implications for research and practice are critically evaluated (Taggart & Chaplin, 2013).

The forth section of this book explores developmentally and socially inappropriate behaviours associated with both neurodevelopmental conditions and challenging behaviour in adults with ID. Chapter 15 explores the relationship between ADHD (Attention Deficit Hyperactivity Disorder) and ID. Identification of neurodevelopmental comorbidities is important due to important implications for diagnosis as well as treatment and prognosis. The evidence for the validity of the diagnosis of ADHD in this population is critically discussed and evaluated (Xenitidis, Maltezos, & Asherson, 2013).

Despite the fact that rates of autism are generally higher among people, ID prevalence studies remain inconsistent as to whether the presence of autism spectrum disorders in ID results in greater risk for comorbid psychopathology. Chapter 16 provides a critical review of evidence showing that those with autism and ID are at greater risk for mental health problems than those without autism. The chapter also highlights differences in autism-specific coping strategies that may remain unrecognised in mental health research in autism and ID (Bradley, Caldwell, & Underwood, 2013).

Chapter 17 is devoted to the relationship between challenging behaviour and psychopathology in ID. Measures designed for the assessment of challenging behaviours in ID with or without ASD are critically evaluated as well as treatment interventions such functional assessment but also the controversial issue of psychotropic drug treatment (Rieske & Matson, 2013). Chapter 18 focuses on offenders with ID in prisons. Adults with ID that are likely to be overrepresented in parts of the Criminal Justice System (CJS) are mostly male, from deprived social backgrounds, have mild or moderate (non-severe) disability and often have mental health needs and comorbid neurodevelopmental disorders, including ASD and ADHD. Importantly, offenders with ID have wellrecognised vulnerabilities such as not understanding the process or their rights, being suggestible during interview and making unwise, sometimes fatal, decisions at crucial points of the forensic pathway (Murphy & Mason, 2013).

The last section of the book covers treatment interventions and service development issues reflecting on ways of improving health provision and wellbeing among those with ID and comorbid mental health problems. Chapter 19 presents a review of the use of psychopharmacology in the management of problem behaviours and evidence for the effectiveness of psychotropic medication based on systematic reviews (Deb, 2013). Chapter 20 provides an up-to-date critical evaluation of the evidence base of psychological treatments people with ID. Effective psychological treatments may lead to improvement in the quality of life of patients with ID, and their carers, and can potentially result in economic benefits to society, such as avoidance of resources wasted on ineffective or harmful therapies (Sturmey & Hamelin, 2013).

Community services are reviewed in Chap. 21 where policy and different models of care are evaluated in the context of service delivery for adults with ID. This chapter examines these issues and looks at the development of evidence base for community mental health services and future models (O'Hara, Chaplin, Lockett, & Bouras, 2013). Chapter 22 provides a review of key issues concerning inpatient mental health services for people with ID. With the deinstitutionalisation movement, the purpose of hospitalisation has shifted to short-term treatment of acute psychiatric issues. The review focuses on research evidence on two main models of inpatient care: mainstream/general services vs. specialist units (Lake, Balogh, & Lunsky, 2013).

## Implications for Research, Policy and Practice

One main objective of this book was to provide a reflection of current practice and research as well as the implications for future clinical practice and service delivery. Chapter 23 therefore concludes with a discussion of key themes for future research and clinical practice. In this final chapter, the importance of developing care pathways for people with ID and comorbid psychopathology is discussed with emphasis on care personalised to the needs of the individual. The editors and co-authors of this chapter propose that clinical research and practice would greatly benefit from the use of structured assessments and evidence-based interventions linked to measureable outcomes becoming part of daily clinical practice within these Care Pathways to support future research. Such a systematic, accurate and detailed routine collection of clinical, genetic and behavioural data has the potential to increase substantially our understanding of the complex interplay of genetic, biological and environmental factors in the presentation of comorbid psychopathology in people with ID and to inform policy and clinical practice (McCarthy & Tsakanikos, 2013).

#### References

- Alim, N., Paschos, D., & Herne, M. (2013). Principles of clinical assessment. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Bradley, E., Caldwell, P., & Underwood, L. (2013). Autism spectrum disorders. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Deb, S. (2013). Psychopharmacology. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Ecker, C. (2013). Neuroimaging. In E. Tsakanikos & J. McCarthy (Eds.), *Handbook of psychopathology in*

adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.

- Flynn, A. (2013). Personality disorders. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Hamelin, J. P., Maum, L., & Sturmey, P. (2013). Classification and diagnostic systems. In E. Tsakanikos & J. McCarthy (Eds.), *Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice*. New York, NY: Springer Science.
- Hassiotis, A., Stueber, K., Thomas, B., & Charlot, L. (2013). Depressive and anxiety disorders in intellectual disability. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Hemmings, C. (2013). Schizophrenia spectrum disorders. In E. Tsakanikos & J. McCarthy (Eds.), *Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice.* New York, NY: Springer Science.
- Lake, J., Balogh, R., & Lunsky, Y. (2013). Inpatient mental health services. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Magiati, I., Tsakanikos, E., & Howlin, P. (2013). Psychological factors. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Maulik, P., Harbour, C. K., & McCarthy, J. (2013). History and epidemiology of intellectual disability. In E. Tsakanikos & J. McCarthy (Eds.), *Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice.* New York, NY: Springer Science.
- McCarthy, J., & Tsakanikos, E. (2013). Key themes for future research and clinical practice. In E. Tsakanikos & J. McCarthy (Eds.), *Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice*. New York, NY: Springer Science.
- Moss, S., & Hurley, A. D. (2013). Integrating assessment instruments within the diagnostic process. In E. Tsakanikos & J. McCarthy (Eds.), *Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice.* New York, NY: Springer Science.
- Murphy, G., & Mason, J. (2013). People with intellectual disabilities and offending behaviours. In E. Tsakanikos & J. McCarthy (Eds.), *Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice*. New York, NY: Springer Science.

- O'Hara, J., Chaplin, E., Lockett, J., & Bouras, N. (2013). Community mental health services for people with intellectual disability. Services. In E. Tsakanikos & J. McCarthy (Eds.), *Handbook of psychopathology in* adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Paschos, D., Bass, N., & Strydom, A. (2013). Behavioural phenotypes. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Rieske, R. D., & Matson, J. (2013). Behaviour problems and psychopathology. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Strydom, A., & Sinai, A. (2013). Dementia. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.

- Sturmey, P., & Hamelin, J. P. (2013). Psychological treatments. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Taggart, L., & Chaplin, E. (2013). Substance misuse. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Winterhalder, R., & Ring, H. (2013). Epilepsy. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.
- Xenitidis, X., Maltezos, S., & Asherson, P. (2013). Attention deficit hyperactive disorder in intellectual disability. In E. Tsakanikos & J. McCarthy (Eds.), Handbook of psychopathology in adults with developmental and intellectual disabilities: Research, policy and practice. New York, NY: Springer Science.