

Textbook of Psychiatry for Intellectual Disability
and Autism Spectrum Disorder

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 Springer

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Foreword

People with Intellectual Disability (ID) are a diverse group of people with individual needs. Aetiological factors associated with ID have an impact on the origin and course of mental health problems and on the type of therapeutic interventions that would be most appropriate for them.

Historically, it was believed that people with ID were being incapable of having mental health problems. However, epidemiological studies over the last few decades consistently disproved this, showing that people with ID have a higher frequency of mental health problems than the general population. The occurrence of mental health problems in people with ID varies according to methodology used for their estimation. An increased vulnerability to mental health problems for people with ID is likely to be due to an increased incidence of brain abnormalities including associated epilepsy, physical and sensory problems, social and psychological hardships, and misfortunes. The severity of ID, adaptive behaviour and social skills deficits are also related to the presence of mental health problems for people with Autism Spectrum Disorders (ASD).

The current textbook of “Psychiatry for Intellectual Disability and Autism Spectrum Disorder” is a welcome addition to the few existing textbooks related to mental health problems for people with ID. Written by a large group of international multi-professional contributors and edited expertly by experienced editors, led by the recognised expertise and proficiency of Dr Marco Bertelli, under the auspices of the World Psychiatric Association (WPA), presents the up-to-date evidence base in the field. Dr Marco Bertelli is credited with his long-standing systematic contribution for the enhanced involvement of the World Psychiatric Association to mental health problems of people with Intellectual Disability. He was fellow at the 12th (Yokohama 2002) and 13th (El Cairo 2005) WPA World Congress, chair of the WPA Section on Psychiatry of Intellectual Disability and WPA Lifetime Honorary Member since the 15th World Congress (Buenos Aires 2015).

The authors of the different chapters provide arguably a worldwide perspective of the research summarising the key topics in the mental health of ID field. A distinct difference of the current textbook includes several contributions on conceptual, cultural, ethical and spiritual issues as well as human rights and broad health issues relating to people with ID. There are also important contributions relating to people with ASD who are known having a high prevalence of comorbid anxiety, obsessive compulsive and attention deficit hyperactivity disorders (ADHD). In reviewing each area, the authors have included recent advances, and many have offered pointers to further progress. In addition, this book is a comprehensive resource for clinical practice including those underpinning assessment, management and service delivery.

The process of deinstitutionalisation and the development of community care of ID services, which took place in the latter part of the 20th century, brought up the complexities of meeting the mental health needs

of people with ID. The introductory chapters on definition, new terminology of Intellectual Developmental Disorders, nosology, epidemiology and prevalence offer insight into the underline debate and conceptual concerns. Considerable improvement has been documented for the assessment and diagnosis of mental health problems for people with ID. This is highlighted in this volume by leading experts of international recognition. Reliable tools and methods that have been developed and are used in clinical practice and research for the assessment and diagnosis of mental health problems in both adults and children with ID are lucidly described.

The aetiology, symptomatology and treatment methods of the core psychiatric conditions are presented on an updated evidence and practice base. The controversy on psychiatric versus behavioural problems or challenging behaviour remains a thorny issue that is further explored. Challenging behaviour, such as aggression, is often the primary reason people are referred to ID and mental health services, and they can often fluctuate over years and be chronic in duration. The overlap between psychiatric conditions and challenging behaviours in people with ID and low-functioning autism should neither be over nor under-played because it has significant clinical and service implications. In clinical practice, it is not always possible to precisely separate psychiatric conditions from behavioural problems in people with ID. It is likely that there is a combination of biological, social and environmental factors interacting with cognitive and adaptive deficits to make people with ID vulnerable to mental health and behavioural problems.

As the population of ID survives longer into old age, aspects of mental health previously not considered relevant have become more prominent. For example, in adults with Down syndrome who now are surviving well into their sixties, a considerable percentage at the age of 50 years have a clinical diagnosis of Alzheimer's disease. This issue is also discussed from research and clinical points of view.

The need for a bio-psychosocial approach, including coordinated multidisciplinary input, is of paramount importance. After decades of community care, unanswered question remains about the appropriateness of generic mental health services versus specialists services for meeting the mental health needs of people with ID. The arguments and the existing evidence base in favour and against mental health systems are rehearsed in this volume and should be of help to policymakers, practitioners and researchers. The number of possible interfaces between services is increasing. Together with existing uneven financing systems, these interfaces are increasingly struggling to manage personalised care pathways adjusted to the needs of people with ID and mental health problems, their careers and families.

The needs of people with ID and offending behaviour, several of whom having also additional mental health problems was overlooked with the deinstitutionalisation. Service provision has lagged developments for local services in countries such as UK, resulting in many people with ID and forensic needs to have been placed in residential facilities a long way from their local communities and at times in unnecessary restrictive environments. The authors of the relevant chapter, having

extensive knowledge and experience, suggest that care for people with ID and forensic needs requires strong interfaces and partnership between ID, mental health and forensic services.

The concluding chapters of the book refer to cultural, spiritual and human rights issues. Cultural aspects vary together with deep-rooted traditions and values that are reflected in the quality of care for people with ID and or ASD. Furthermore, people with ID have the right to spiritual expression and practice of beliefs. The protection of human rights is of utmost importance where prejudices and barriers are removed and everyone can live without being stigmatised.

A strategic approach needs to be adopted to ensure effective person-centred services where there are care pathways that connect health and social care, support and education services as when a person might need these services. Despite progress, there is still a need for clear interfaces with services, joined-up working between different agencies, proactive commissioning strategies, development of academic centres and further research into service models and outcomes.

This volume presents an evidence-based comprehensive publication for the mental health problems of people with ID and or ASD. An obvious question is how the outcomes produced by research can be translated for the benefit of people with ID, their families and their careers. The transformation of care for people with ID over the last half a century includes the movement towards integration, participation and choice as well as civil and human rights movements on a national and international level. There is now a consensus on the need to respond more adequately to mental health needs in this population. The current trends are geared towards community integration and schemes with service users' participation at all levels, including design and implementation by using a person-centred approach. Despite the existence of policies and services for people with ID, recognition of and provision for their mental health needs carry low priority. This gap is greater in low and middle-income countries, where the burden of disability needs to be recognised to plan for and meet the needs of those with developmental and intellectual disabilities across their lifespan. It remains to be seen how people with ID experience the reality of equality and absence of discrimination and whether stigma and negative attitudes by others will be eliminated.

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Preface

Since I entered University to become a medical doctor, I have always loved research. I think research is fundamental for clinicians to the same extent to which clinical challenges represent a base for research. Medical research is also a unique opportunity to identify or operationalise things that can improve humans' health and quality of life.

Halfway through my training in medicine, I felt that most of the medical specialisations would not have met my interest in philosophy and humanities developed during my previous studies at the high school, but fortunately I discovered psychiatry as a discipline implying a complex approach to human suffering and thus able to combine all my interests. I thought that entering the mind of persons with schizophrenia or other major psychiatric disorders and helping them to recover could be the most satisfactory thing I could ever do as a medical doctor. Thus I was very disappointed when in response to a request for a topic for my graduation thesis, the Professor of Psychiatry imposed me a research on intellectual disability, mental retardation at that time, which was largely considered the "Cinderella of psychiatry".

Nevertheless, I was looking forward to working as a psychiatrist in a real clinical way and my main desire was to complete my training and to graduate, so I decided to accept. I can now say that this apparently unlucky obligation was one of the greatest opportunities of my life. In fact by entering the field of mental health of intellectual disability, I increasingly realised that I was getting in touch with the most complex pathogenic and phenomenic aspects within psychiatry and the best chances to help other persons to soothe their mental suffering and bring a contribution in life to make a better world.

In the last century, intellectual disability and autism have been neglected by psychiatry for a long time and still are, although in the previous century psychiatry had a well-established and well-documented role in promoting an appropriate care for what was called mental retardation. According to Frank Menolascino, who can be considered one of the founders of modern psychiatry of intellectual disability, this withdrawal resulted "in a number of stereotyped views or blindspots ..., that are: uncritical acceptance of mental age as an adequate description of a person; treatment nihilism ... associated to the overriding focus on chronicity and irreversibility; and excessive focus on the severely retarded in contrast to the mildly retarded".

In the last 15 years, the interest in autism has grown a lot in the psychiatric field but not that for people with the greatest need of support, such as those with minimal verbal ability or low IQ, to whom the main attention is given in this textbook. In most countries across the world, persons with intellectual disability and low-functioning autism still face great difficulties in accessing mental health service and in receiving adequate assessment and care. Specific training of mental health professionals is also lacking, at both undergraduate and graduate levels.

This neglect has always been unfair and inappropriate to me. Unfair because persons with intellectual disability and low-functioning autism

would deserve, as persons, at least the same attention as all other persons, but even more for their higher difficulties and risks in daily life and higher vulnerability to the full range of psychopathological features.

Many of the current limits to an appropriate mental health care and more generally to community inclusion are linked to the conceptualisation of intelligence, as a unitary capacity which defines human nature in its most important transcendental component. The persistent IQ reduction confines persons with intellectual disability into a condition of eternal sickness or eternal childhood as well as into a persistent position of inferiority and unworthiness, which many persons with intellectual disability end up identifying with. In reality, it has never been demonstrated that unitary intelligence is an entity of nature and not a mere human construction. Nor has it ever been proven that the mind and the body represent two dichotomous realities.

The study of the human psyche has been characterised for many years by a clear separation between body and mind but also between affectivity/emotionality and cognition/intelligence. In traditional cognitivism, body processes were seen essentially as by-products of cognition, and as too little specific to be able to contribute to the variety of emotional experiences. The embodied vision of the mind has not yet been adopted in theories of emotionality, despite the fact that the body has always occupied an important place in the study and characterisation of emotions, from Darwin onwards. To date, the level of knowledge on the inter-relationship between emotionality, corporeality and cognition absolutely does not allow us to consider people with intellectual disabilities and autism as limited in their humanity.

In addition to being unfair, the scientific community's neglect of the mental health of people with intellectual disabilities and low-functioning autism has also been inappropriate because the development of scientific knowledge in this area has general important implications for the entire neuroscientific field, such as the understanding of the link between early specific cognitive deficits and psychopathological vulnerability, the definition of the grade of adjunctive functional impairment and clinical distress associated with the co-occurrence of psychopathological conditions, the possibility to identify psychiatric symptoms in patients with cognitive and communicative limits, basing on observable and behavioural changes from the baseline, and to distinguish them from the features characteristics of the developmental conditions. Furthermore, psychiatry of intellectual disability and autism is looking for the most useful way to combine developmental/idiographic (narrative) and nomothetic approaches to mental suffering and to implement person-centred outcome measures, such as generic quality of life. Even models of care (residential care, respite care, multidisciplinary approach to care, etc.) and social issues of health (stigma and labelling, self-advocacy, etc.) that were first developed in the intellectual disability field are now widely used in general psychiatry and other neuroscientific disciplines. Many contributions are also being brought on how individual cognitive, emotional, behavioural and relational characteristics emerge and change across early and lifetime development of the brain, and how they can be altered and manifest as mental health conditions or mental health

problems. Recent findings in neuroscience display that many of what have been traditionally considered to be distinctive forms of psychopathology have features in common with one another, co-occur, present in the same person across the life span or represent age-adjusted variations of common underlying dispositions. Genome-wide association studies increasingly show that copy number variants of several syndromes including intellectual disability and autism are present also in many other major psychiatric disorders such as schizophrenia, bipolar disorder and major depressive disorder. Most developmental, psychiatric and neurological disorders have recently been proposed to be part of a unique group of disorders affecting neurodevelopment.

Thus, the present textbook places intellectual disability and autism at the very centre of neuroscience in general and psychiatry in particular, anticipating a position that will soon be embraced by the entire scientific community.

People with intellectual disabilities and autism are an asset to the world community on many levels. On a conceptual level, because they value the diversity and fragility foreseen by nature for the neuropsychic system of the human being, on a concrete level, because in the right context they can make their own contribution to society, and on an evolutionary level, because they help the humankind to overcome its limits and to acquire increasing capacity for attention and balance with the essential aspects of their existence.

This textbook represents for me a major milestone in the long path of research and clinical practice. Its preparation spanned over 4 years, amidst numerous difficulties, unforeseen events, the COVID-19 pandemics (after which we added a chapter focusing on teletraining and teleassistance) and the need to keep updated the chapters already completed. This book was inspired by the will of sharing knowledge and transmitting passion to colleagues, especially young and future colleagues. In fact, it is intended for use by graduate students and trainees of university faculty, practitioners in clinical disciplines or management roles in developmental disabilities services and education, and to a lesser degree, undergraduate students, parents, attorneys and advocacy groups. Faculty will find this book particularly useful as a primary course text at the graduate level. Researchers will find the coverage contained herein useful for a summary of current knowledge about a subarea of psychiatry of intellectual disability and low-functioning autism that is new to them or that intersects their own specialty in the wider field of developmental disabilities. Practitioners and educators can use the textbook as a resource to point to when there is a doubt or a debate regarding diagnostic issues, appropriate treatments or intervention practices.

The overall purpose of this textbook is to provide readers with a complete and up-to-date overview of the state of knowledge in the field of psychiatry for persons with intellectual disability and autism.

I have invited the wide majority of most authoritative authors to contribute to the textbook in order to provide readers with the very best and up-to-date knowledge, and to reflect the growing awareness of the mental health needs of people with intellectual disability and autism across many countries and cultures.

Authors were asked to yield foundational conceptual information on their assigned topic, to identify valuable studies in the related literature, to emphasise the latest research findings and to provide clear conclusions and interpretations.

There is variation across the chapters in terms of length and focus, which is mainly a reflection of the evidence base available on specific issues. I have also allowed some overlaps, as for the numerous and strong links between the different aspects of mental health in this field and an interdisciplinary approach.

Not all the issues concerning the complex field of psychiatry of intellectual disability and autism have been deepened as I would have liked. I hope that I will still be given time and energy to produce increasingly precise and useful updates and insights in the coming years. Nevertheless, as far as my knowledge, the present work represents the most comprehensive and up-to-date textbook worldwide in the field of mental health of neurodevelopmental disorders, with the highest number of chapters and eminent authors from across the world. It has been realised under the aegis of the World Psychiatric Association within its 2021–2023 action plan.

It can be considered an essential reading also for future prospects, as it displays how we started moving into a new century of discovery, evolution, and high-quality care for people with intellectual and developmental disabilities.

Marco O. Bertelli, Leading Editor
Florence, Italy

Acknowledgments

This textbook has been realised thanks to the precious contribution of a stellar group of world-renowned authors, 116 leading experts in the field of mental health of intellectual and developmental disorders from around the world. I am deeply grateful to all of them for their diligence in writing the chapters and for their willingness to accept my recommendations, integrations and various other requests along the way. Special thanks go to Dr. Shaun Gravestock, who worked on his part until a few days before passing away from COVID-19, and his partner, Darren Ward, who took care to find and pass on Dr. Gravestock's work to me in times of extreme grief.

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The present textbook represents an important outcome in my long path through the field of psychiatry of neurodevelopmental disorders, which started with Dr. Giampaolo La Malfa and Professor Pier Luigi Cabras at the Operative Unit of Psychiatry, Department of Neurological and Psychiatric Sciences of the University of Florence, Italy, during which I met many people who have fuelled my passion, informed my knowledge and inspired my research and clinical activities. I want to thank them all.

My career in the World Psychiatric Association (WPA) has begun in 2001 at the Antalya (Turkey) WPA Regional Meeting, where I delivered a speech in substitution of Professor Giovanni Stanghellini and where I met Professor Juan Mezzich who encouraged me to apply for a fellowship for the 2002 Yokohama World Congress (Japan). I am deeply grateful to Professor Mezzich for this opportunity and for his constant presence during my WPA career. During the Yokohama fellowship and the following one at El Cairo, Egypt, I had the extraordinary opportunity to be trained by leading international experts and to share opinions and experiences with young colleagues from all around the world. I could also progress my activities within the WPA Section "Psychiatry of Intellectual Disability" which I had started few years before the Antalya congress. Professor Nick Bouras and Professor Luis Salvador-Carulla have been my guides within the Section and other related assignments. I want to thank them for the knowledge and the constant support they provided to me during my tenure as the Section chair and the other commitments within the WPA, including the creation of this textbook. I received an extraordinarily intense albeit brief contribution from Professor Ludwik Szymanski in a meeting with him that represented a physical contact with the origins of the Section and the history of psychiatry of intellectual disability.

Thanks also to Professor Mario Maj, the WPA President during 2008–2011, and his Executive Committee, who awarded me the WPA lifetime honorary membership at the end of the first of my two terms as Section chair and who helped to sustain my enthusiasm to write this textbook. Other WPA leadership figures who have shown respect for me and whom I want to thank are Professor Norman Sartorius, the WPA President during 1996–1999 who was my mentor all along my WPA training, Professor Levent Kuey, the WPA Secretary General during 2008–2011, and more recently Professor Afzal Javed, the current WPA President, who has included mental health needs of people with neurodevelopmental disorders in the priorities of the 2020–2023 WPA action plan and who entrusted me with the chairing of the working group on autism spectrum disorder, one objective of which is to produce this textbook. I also thank Professor Michel Botbol and Professor Norman Sartorius for their particular interest in the production of this textbook and highlighting its cultural and scientific importance on the world scene.

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My ideas and arguments have also benefited from enormously helpful feedback I have received in presenting parts of these textbooks at the EAMHID International Congress I organised in Florence in September 2015 and at the last three WPA World Congresses, in Mexico City, Lisbon and Bangkok (virtual). The rich ideas and discussions at these meetings have broadened my scientific and cultural horizons and have given me a new critical perspective on my work.

My understanding of neurodevelopmental disabilities, both as lived experience and as an area of academic and clinical practice, has been greatly enhanced through the dialogues and interactions with persons with intellectual disabilities and/or autism spectrum disorders and their family members as well as through the conversations with professionals and scholars within and beyond the mental health field. I want to acknowledge Professor Giovanni Stanghellini for his extraordinary insights and innovative perspectives in psychopathological phenomenology and philosophy, Dr. Carlo Francescutti, whose views increased my research attention to the interdisciplinary working in daily practice and whose passion for this field continues to encourage me, Dr. Maria Luisa Scattoni for her extraordinary neuroscientific knowledge that ranges from basic research to the multidisciplinary organisation of interventions and services, Dr. Serafino Corti for his invaluable assis-

tance and involvement in both the reform of national scientific societies and the increasing strengthening of the activities that emerged, and Professor Ivan Brown, who introduced me to the deeper dimensions of whole-person quality of life and their importance in evaluating the outcomes of any intervention. I also want to offer special thanks to two fellow psychiatrists who I am honoured to count among my closest friends, Dr. Michele Conte, whose great culture, critical spirit, and “visionary” skills have challenged my convictions and stimulated important improvements on several occasions, and Dr. Michele Mancini, whose ample experience in clinical research has animated many productive discussions on some of the key topics of this work.

I am fortunate to have found in the last decade welcoming intellectual home at “Fondazione San Sebastiano della Misericordia di Firenze”, whose General Director, Dr. Leandro Lombardi, and the whole board of directors shared my belief that clinical research, detection of needs and dissemination of new knowledge represent a greater gift to others than material goods. Thanks to Dr. Alessandro Burberi, President of the San Sebastiano Foundation, and all the members of the scientific committee of CREA (Research and Clinical Center), who have always appreciated the production of this textbook and eagerly awaited its realisation.

Almost eight centuries have passed since “Misericordia di Firenze” was founded, during which it has never interrupted its mission of charity and solidarity, constantly trying to keep up with the times without disrespecting the historical and social context in which it was called to operate, blending modernity and tradition. Special thanks go to Dr. Andrea Morino and Dr. Alvise Revedin, respectively Vice-secretary and Secretary of “Misericordia di Firenze”, who strongly supported the establishment of CREA and valued its activities, including the realisation of this textbook.

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Marco O. Bertelli

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