Preface

Intellectual Disability (ID, previously known as mental retardation) is a condition of arrested or incomplete development of the mind. ID is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities.

In the past decades, research in the area of intellectual disability has helped in a phenomenal way to change the attitude toward the condition as well delivery in various multidisciplinary services to affected individuals. New ways for assisting these individuals with focus in understanding and managing significant issues and thereby integrating them into the mainstream society has been the aim every research being conducted.

Keeping it in mind this book is designed with the objective of providing students and professionals who work with individuals with intellectual disability a literature which focus on historical development of intellectual disability as a debilitating condition, awareness and attitudes toward intellectual disability, issues pertaining to mental health, schooling, sexuality, parenthood, crime and law, and quality of life of individuals with intellectual disability, issues faced by family members, assessment and management, psychosocial treatment, use of assistive technology and vocational rehabilitation.

To be more specific, Chapter 1 gives an overall view about the history, changes in terminology, classification, epidemiology, etiology, comorbidities and management of intellectual disability. Also, current understanding and latest trends and issues are highlighted.

Chapter 2 deals with developmental vulnerability and mental health. It gives an account of the prevalence of psychiatric disorders and its nature in individuals with intellectual disability. It looks into the consequences of this comorbid condition on individuals, families and the wider community, and also the various challenges in identifying and managing these concerns. Issues such as applicability of standardised psychiatric classification systems, gaps in service delivery models and access to such services, as well as unmet training need are also focussed in this chapter.

Chapter 3 concentrates on the topic school bullying and students with intellectual disabilities. The history of research in school bullying which has looked into the nature, extent, causes, and consequences of school bullying and recent research on cyber bullying, bullying using information and communication technologies, research on school bullying involvement among students with disabilities, particularly those with intellectual disabilities is provided in this chapter. Along with multidisciplinary research details the chapter also has recommendations for public policy and prevention programs as well as future research.

Chapter 4 discusses the mental health issues among family members of children with mental disability. It looks into the types of problems faced by the children with mental disability, their parents and siblings, including the possible impact on mental health of the family. The chapter as well discusses the
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impact of mental health difficulties in parents and its impact on parenting. It intends to highlight the need to recognise parents who are struggling, what professionals should look for in their assessment of families with children with intellectual disabilities.

Chapter 5 deals with stress and adjustment issues in the family of children intellectual disability. It looks into wellbeing, coping and overall adjustment of parents, siblings and other family members of children with intellectual disability and also research carried out in this area. Intervention techniques for helping families cope with issues associated with having a member with intellectual disability is also discussed.

Chapter 6 deals with stress and resilience in parents of intellectually disabled children. It presents a study which attempted to find out the factors of stress that could act against the resilience in the parents of intellectually disabled children. The sample consisted of 50 parents of intellectually disabled children from different panchayats in the Calicut, Kannur, Wayanad districts in the state of Kerala, India. Results of the study indicate that extra-familial stress was a negative predictor of resilience in the parents of the intellectually disabled children. Further, the parents who were in a late part of the young adulthood period and old were relatively more resilient than the parents who were in the earlier part of the young adulthood period.

Chapter 7 focuses on the role of family members as caregivers of individuals with intellectual disabilities. It looks into the experience of caregivers of persons with intellectual disabilities, factors that exacerbate caregiver stress and facilitate caregiver gain while reviewing the research in this field, and research about parents, siblings and grandparents as caregivers in different cultural settings. Factors with regard to parents such as age, severity, birth order, problem solving and coping mechanism, experiences of both mothers and fathers, their marital relationship, bereavement experiences are also focussed. Experience of siblings is explored in depth with regards to their feelings towards a sibling with Intellectual Disability, expectations about responsibly etc. Finally, the role of stigma, families in context, poverty, support staff and guidelines for caregivers and support system are also explored.

Chapter 8 explores the quality of life of people with intellectual disability. The need to understand the quality of life of people with intellectual disability is crucial as this mental disability is considered to be a major setback for any individual and his/her family. It needs to be highlighted here, that the families of people with intellectual disability also play a crucial role. New research reviews are required to bring policy changes and better tools.

Chapter 9 outlines 21st century perspective of assessment and management of communication skills in individuals with intellectual disability. The development of communication skills according to different perspectives, communication skills in individuals with intellectual disability and associated issues, their assessment and intervention is covered comprehensively in this chapter.

Chapter 10 covers issues and recent trends in the assessment and management of intellectual disability in childhood. It is an attempt to understand disability aspect in general and assessment aspect extensively. Both the classic and latest trends of assessment techniques have been looked into. It include assessment categories on different dimensions of ability, emotions and behaviours such as intelligence, achievement, adaptive, social behaviour and emotional adjustment, communication/language, sensory status, motor skills, and health status. The issues concerning the assessment of children with intellectual disabilities, including definitional problems, psychometric factors, and practical difficulties is emphasized and measures would be proposed to help students, counsellors, teachers, and psychologists.
Chapter 11 explores the concerns for individuals with intellectual disability in India. It focuses on topics like legal services available for persons with intellectual disability, challenges faced by parents, health issues, sexual knowledge, marriage, quality of life, and old age, attitude of society towards the individual with intellectual disability, implications, management and prevention for future improvement for individuals with intellectual disability.

Chapter 12 provides awareness towards intervention for intellectual disability. There are many issues which require attention while dealing with ID like human resources, quality training of clinical psychologists in India, the conflicts among the team approach, acceptance in the family and society and many more. There are 1.5 million people with intellectual disability in India. However, experts working in the field of developmental disabilities feel that prevalence is much higher. The population with ID is increasing but the resources to deal with these issues are few. The mental health profession is a multidisciplinary one. The psychiatrist, the clinical psychologist and the psychiatric social worker all have their significant role in the management of ID. There is a long way to go. There are many things that can be offered but what we need is acceptance in our society of such people and Awareness towards Intervention.

Chapter 13 discusses about attitude towards People With Intellectual Disabilities (PWID). It delves into the history on PWID to understand the existence of stereotypical attitudes towards PWID. This chapter also presents with the stress, stress related issues faced by families of PWID. It discusses how families often cope with these issues and its effect on providing timely assistance and rehabilitation of PWID. Also, attitude of stakeholders like siblings and relatives, teachers, educationists, health professionals, general public and future recommendations for service and research are also discussed.

Chapter 14 deals with psycho-social treatment of intellectual disability and current trends in it. Applied Behaviour Analysis has the most research evidence base for treatment of challenging behaviours and improving the quality of life of these individuals. Applied Behaviour Analysis adopts a systematic approach in assessment and treatment of challenging behaviours. In recent years, ‘parenting’ has also emerged as a dominant theme among researchers and practitioners. Emerging research evidences are also favouring ‘parenting skill based programmes’ grounded in behavioural research as intervention strategies to obtain better developmental outcomes for individuals with intellectual disability.

Chapter 15 covers recent trends and issues in vocational rehabilitation of people with intellectual disability. The rights of people with disabilities have been given new attention with the entry into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in May 2008. The various policies, issues and trends in vocational rehabilitation of people with intellectual disabilities in existence in different countries need to be examined along with different models in existence to develop appropriate executable models whereby such rehabilitation services could be made available early in life to such individuals and after training they could be provided with supported employment or integrated employment as the case may be.

In chapter 16 the vocational rehabilitation of persons with intellectual disability, recent trends and associated issues is discussed. A summary of key issues in vocational rehabilitation for individuals with intellectual disability, nature of vocational rehabilitation in in mild, moderate and severe intellectual disability, principles of rehabilitation for individuals with intellectual disability, assessment of intellectual disability and it’s limitations. It reviews the need for vocational rehabilitation, assessment required for rehabilitation and barriers of vocational rehabilitation for individuals with intellectual disability. The vocational rehabilitation process and preparation of the individual for rehabilitation is covered subsequently. Finally, it presents social skills training and newer trends in rehabilitation like use of virtual reality and sensory integration.
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Chapter 17 focuses on the use of assistive technology to empower persons with intellectual disabilities. It highlights the importance of using assistive technology to help persons with intellectual disabilities and make them independent in all spheres of life. Empirical studies suggest that assistive technology is effective in improving the quality of life of persons with intellectual disability and ensures independence for them. This chapter is an investigation of available research evidence on the use of assistive technology in intellectual disability, discusses utilizations, impediments/barriers, implications and suggests recommendations for future research.

Chapter 18 concentrates on crime and legal issues among intellectually disabled individuals. It presents with research on criminal law and the different forms of aggressive behaviour such as sexual violence, homicide, theft, and arson and alcohol-drug abuse associated with intellectual deficiency. This chapter also provides information on research regarding civil law and the most common problems for individuals with intellectual deficiency, such as financial capacity and capacity for medical consent, issues regarding the trial and conviction for individuals with intellectual deficiency and also recent research on attitudes toward intellectual deficiency and legal issues. Neuropsychological and cross-cultural perspectives of the issues are also presented.

Chapter 19 reviews literature with regard to parents with intellectual disability. It also attempts to review literature on the data available about parents and issue of parenting with intellectual disability in the Indian context while concentrating on directions for future research. Research studies’ focussing on parents with intellectual disability is scarce. Available research primarily addresses the question of whether or not individuals with intellectual disability can be adequate parents or reports on methods for improving their parenting skills. There has been relatively negligible work in the Indian context with regard to parents with intellectual disability.

Finally, Chapter 20 deals with sexuality, parenting skills, and associated issues in persons with Intellectual Disability. Sexuality has an active role in the development, evolution, emotional balance and affective stability of the individual. It has a significant role in interpersonal and couple’s relationships. As intellectually disabled person approach puberty their control of behaviour and expression of sexuality may manifest in unacceptable ways. Persons with intellectual disabilities are at increased risk for physical, sexual and emotional abuse. This chapter focuses on the issues related to sexual feelings and its expression among intellectually disabled people and the risk for sexual abuse. The necessity of sex education and components of sex education for different group is also explained in detail. The chapter also addresses the parenting skills and problems related with parenthood among individuals with intellectual disability.

This handbook was aimed to provide the latest empirical research findings in the area of Intellectual disability focusing on epidemiology, assessment, causes, and comorbidities, intellectual disabilities at various stages (childhood, adolescence, and adulthood), educational and vocational issues, sexuality, marriage and parenting issues, forensic issues, stigma, and mental health problems among family members. It would also provide a fresh approach and comprehensive knowledge on ID and its various aspects and I think the chapters have done justice to the objective of the handbook.

I am hopeful that the target audience of this Handbook (composed of professionals and researchers working in the mental health area such as clinicians (especially Psychiatrists, Clinical Psychologists, Pediatricians), academicians, special educators, social workers, Psychiatric nurses, rehabilitation centres, and students in the area of mental health) would be benefited from this handbook. This handbook is useful for Universities, hospitals, and the public. Moreover, it would provide a deep knowledge on ID and
its various issues from a developmental approach and it is valuable as it deals with their sexual issues, marriage, parenting skills and issues faced by the family members. It will further enrich our current knowledge of intellectual disabilities. I hope this handbook will be another stepping stone to understand intellectual disabilities in a more comprehensive way.

The research works cited in this book is referenced according to APA guidelines.

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Rejani Thudalikunnil Gopalan
Gujarat Forensic Sciences University, India