Chapter 1

Introduction

Introduction and aims of the book

The changing patterns of care and the movement away from institutions to community living have laid to rest the myth that the psychological problems suffered by those with learning disabilities were the result of institutional-isation alone and that living in the community would somehow 'remove' or 'cure' such problems. In fact community living has resulted in additional stressors, for example, negative attitudes, social exclusion, increased exposure to alcohol and illicit drugs and vulnerability to abuse or exploitation. Such stressors, when combined with the limited coping and problem-solving skills that a person with learning disability often has, is likely to result in problems in day-to-day life and mental heath issues. It is evident that many mental health disorders often go unrecognised due to the phenomenon of diagnostic overshadowing, that is, the assumption that mental disorder and learning disability are mutually exclusive categories rather than overlapping.

It is now generally accepted that people with learning disabilities may also suffer from mental disorders seen in the general population, such as anxiety, depression, schizophrenia, dementia and personality disorder (Eaton and Menolascino 1982; Campbell and Malone 1991). The superimposition of mental health disorders in people with learning disabilities is known as *dual diagnosis*. However, this term is also commonly used in acute mental health care to identify people with both a mental health disorder and a drug or alcohol problem. In this book we have followed the former definition, and use the term *people with dual diagnosis* to specify people with learning disabilities who also experience mental health disorders.

The estimated prevalence of dual diagnosis ranges from 10 to 80%, but there is a consensus that 30 to 40% of people with intellectual disabilities experience a range of mental health disorders during their lives. For most of the common mental health disorders, the estimated prevalence in people with learning disabilities is far higher than in the general population. Many learning dis-ability nurses and a significant number of mental health nurses are in daily contact with this group, but their complex needs are not well understood by these health care professionals. This may be attributed to a lack of appropriate

knowledge, skills and confidence in working with people, as well as a general lack of understanding within mainstream mental health services about how learning disability mental health liaison nurses can contribute positively to the co-ordination and the therapeutic delivery of mental health care for this population.

We think that nurses working in the field of learning disability and mental health should have a sound knowledge base for shaping and enhancing their clinical practice. With this in mind, this book aims to explore issues concerning the mental health of people with learning disabilities, including:

- The prevalence, nature and manifestation of mental health disorders in people with learning disabilities
- Issues and models of detection and diagnosis of mental health disorders in people with learning disabilities
- Needs assessment for therapeutic intervention and services
- Pharmacological and psychosocial interventions
- The learning disability nurse as therapist
- Professional and legal issues to enhance safe practice, taking into consideration the vulnerability of people with learning disabilities
- Policy and service perspectives

Developing evidence-based practice is a key theme of this book and we have attempted to focus the issues and practice-based evidence on the aforementioned themes. However, the lack of a significant systematic evidence base poses a challenge for nurses and other health and social care practitioners working in this field. The real challenge here is to reflect on the rich and diverse ways of working with people with dual diagnosis in order to develop a model of practice-based evidence.

In this book, we explore the role of the learning disability nurse as a therapist in working with people with dual diagnosis. We believe that through the consolidation of the evidence base for assessment, intervention and services, learning disability and other nurses will be able to utilise this knowledge in planning and developing therapeutic nursing practices when providing person-centred care for people with leaning disabilities and mental health disorders.

The structure of this book

People with dual diagnosis present unique challenges to health professionals, in terms of both diagnosis and the provision of appropriate therapeutic services. Considering the nature of dual diagnosis, people with a learning disability and mental health disorder will require a mixture of generic and specialist services. The White Paper *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health 2001) indicates that the National Service Framework (NSF) for mental health applies to all people of working

age and therefore is applicable to people with learning disabilities (Department of Health 1999). From an ideological perspective, people with learning disabilities who experience mental health disorders are expected to access mainstream mental health services for mental health care and support. The challenge is for mainstream health and social care services (including mental health services) to provide therapeutic support and help for people with learning disabilities that respects individuality, choice and independence. Both learning disability and mental health services have a long history and we have seen the implementation of a number of Government polices aimed at improving the services for this population. This gives a clear vision of how services are anticipated to develop in the future. The concepts of learning disability and mental health and mental health disorders are explored in Chapter 2.

For many years, professionals from various fields have debated whether people with learning disabilities could become emotionally disturbed or mentally ill (Scheerenberger 1987). People with mild learning disability were thought by carers to be 'worry free', and people with severe learning disabilities were considered to have no feelings (Nezu 1994). Studies published in the last two decades document a high prevalence of mental health disorders in people with learning disabilities (Eaton and Menolascino 1982; Reid 1989; Bouras and Drummond 1992). Such mental health problems can often go unrecognised, as shown by Reiss in his studies on the phenomenon of 'diagnostic overshadowing' (Reiss et al. 1982; Spengler et al. 1990; Sovner and Pary 1993). This refers to instances in which the presence of learning disability decreases the diagnostic significance of an accompanying mental health disorder. Hence, there is a tendency to underdiagnose mental health disorders in people with learning disabilities, because some of the debilitating emotional problems may appear less significant when compared with the effects of learning disability. The extent of overlap between challenging behaviour and mental health disorder has also been the subject of many debates, and its impact on detection and diagnosis of mental health disorders in people with learning disabilities is very confusing. Nurses and other health and social care practitioners need to understand the prevalence, nature and manifestation of mental health disorders in people with learning disabilities in order to conceptualise the issues of providing therapeutic care, and this is explored in Chapter 3.

There is considerable debate about how mental health problems manifest in those with different degrees of learning disability. There is a broad consensus that in those with mild learning disability, such disorders present in a more typical way and can be diagnosed by applying criteria that are used in the general population using *International Classification of Diseases-10* (World Health Organization 1993) and the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* (American Psychiatric Association 1994) with minor modifications, for example as suggested in *DC-LD (Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation* (Royal College of Psychiatrists 2001). There is much more debate about how such disorders manifest in those who have severe to profound learning disabilities. Here

mental health problems often present in atypical, more individualised forms, as behavioural disorders, and assessment requires a more qualitative, case study approach using person-centred planning models and behavioural approaches such as functional analysis.

Unrecognised mental health problems in those with learning disabilities can have a major effect on their general well-being, personal independence, productivity and quality of life, as well as impacting on family and other carers. The combination of learning disabilities and mental ill-health can also give rise to stigmatisation and prejudices which lead to social exclusion. Differential diagnosis of challenging behaviour and mental health disorder may have serious consequences in understanding the therapeutic needs of this particular population and developing effective ways of working. We explore the issues concerning assessment and diagnosis in Chapter 4.

Due to the complex and confusing nature of dual diagnosis, the form and types of needs of people with learning disability who also experience mental health disorders are not well understood by service providers and professionals in this field. It is argued that people with dual diagnosis have intricate needs, which are often poorly identified, and such people are shifted between mental health and learning disability services in fruitless attempts to obtain adequate therapeutic services (Menolascino 1989). This calls for a systematic process of identifying needs and providing appropriate interventions to meet these needs. With this in mind, we explore the concept of need and its assessment for people with dual diagnosis in Chapter 5.

People with learning disabilities make up a diverse group and often have additional physical and sensory disabilities or epilepsy which makes them more vulnerable to suffering from a mental health disorder. A number of factors, broadly divided into developmental/biological, psychological and social, combine to lead to mental disorder in a given individual. Such factors can either increase the risk of mental disorder or in some circumstances protect the person from mental health problems. For example, a person with learning disabilities who has a valued lifestyle with supportive consistent carers would be less vulnerable to additional unpredictable stressors such as bereavement than someone who is living in deprived circumstances with inconsistent carers or support.

Providing therapeutic care to address the mental health needs of people with learning disabilities requires in-depth understanding of the biopsychosocial dimensions of learning disability. Learning disability nurses by virtue of their training and experience play a significant role in health assessment, health facilitation and co-ordination of care in the multidisciplinary environment. The contribution of learning disability nurses in caring for people with dual diagnosis is explored in Chapter 6 using the framework of therapeutic nursing.

Our knowledge base of therapeutic interventions for people with dual diagnosis is slowly expanding. People with dual diagnosis require psycho-pharmacological as well as psychosocial interventions in the treatment of mental

health disorders. We have considered various types of medication used in treating mental health disorders and its application to people with learning disabilities. We have also explored the advances in psychopharmacology, with the introduction of new forms of drugs with minimal side effects. Too often, medication is the sole intervention used in mental health disorders. We believe that the psychosocial interventions such as cognitive behaviour therapy, behavioural and psychotherapeutic approaches are equally as important as medication. Psychopharmacological and psychosocial interventions are explored with available evidence base in Chapters 7 and 8.

Care for people with dual diagnosis needs to be undertaken with professional integrity, respecting the individuality, rights and choices of people. We need to understand the issues of consenting to assessment and treatment and how we can help people with learning disabilities make the right choice. It also involves risk taking and hence it is important for nurses and other health and social care practitioners to have a sound knowledge base in risk and risk assessment. These important issues along with mental health legislation are explored in Chapter 9.

Recent strategic documents such as the National Service Framework (NSF) for mental health disorders and the *Valuing People* White Paper on service development for those with learning disabilities recommend that mainstream psychiatric services should be accessible to those with learning disabilities. When such services are inappropriate, for example due to lack of expertise or vulnerability of clients with learning disability when admitted to a general psychiatric ward, appropriate back-up specialist services should be available. There is continuing debate about how capable mainstream mental health services are in meeting the diverse needs of those with learning disabilities. The role of specialist services and the policy directions for service development are explored in Chapter 10.

To provide therapeutic care, we need to conduct a thorough assessment of the problems and needs of people. These call for the use of structured assessment processes using standardised screening tools, interview schedules, rating scales and checklists. A range of instruments in assessing the mental well-being and behaviour of people with learning disabilities is considered in Appendix 1.

Appendix 2 concludes the book by covering some genetic syndromes related to mental health.

This book will introduce a range of concepts relating to the mental health needs of people with intellectual disabilities. This will include the nature, prevalence, causes and manifestation of mental health disorders in this population. The question of how nurses should assess the needs of people with intellectual disabilities and offer needs-led therapeutic services is addressed. This book will provide an in-depth knowledge base for learning disability and mental health nurses from an evidence-based perspective, which should have an impact on their clinical practice and in service development.

References

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*. Washington DC: APA.

Bouras, N. and Drummond, C. (1992) Behaviour and psychiatric disorders of people with mental handicaps living in the community. *Journal of Intellectual Disability Research*, **36**, 349–357.

Campbell, M. and Malone, R.P. (1991) Mental retardation and psychiatric disorders. *Hospital and Community Psychiatry*, **42**, 374–379.

Department of Health (1999) *National Service Framework for Mental Health. Modern Standards and Service Models*. London: Department of Health.

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: The Stationery Office.

Eaton, L.F. and Menolascino, F.J. (1982) Psychiatric disorders in the mentally retarded: types, problems and challenges. *American Journal of Psychiatry*, **139**, 1297–1303.

Menolascino, F.J. (1989) Model services for treatment/management of the mentally retarded–mentally ill. *Community Mental Health Journal*, **5**, 145–155.

Nezu, A.M. (1994) Mental retardation and mental illness. *Journal of Consulting and Clinical Psychology*, **62**, 4–5.

Reid, A.H. (1989) Psychiatry and mental handicap: a historical perspective. *Journal of Mental Deficiency Research*, **33**, 363–368.

Reiss, S., Levitan, G.W. and Szyszo, J. (1982) Emotional disturbance and mental retardation: diagnostic overshadowing. *American Journal of Mental Deficiency*, **86**, 567–574.

Royal College of Psychiatrists (2001) *DC-LD (Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation)*. London: Gaskell Press.

Scheerenberger, R.C. (1987) *A History of Mental Retardation: A Quarter of Century Practice*. London: Paul H. Brookes.

Sovner, R. and Pary, R.J. (1993) Affective disorders in developmentally disabled persons. In: J.L. Matson and R.P. Barrett (Eds) *Psychopathology in the Mentally Retarded*. Boston: Allyn and Bacan.

Spengler, P.M., Strohmer, D.C. and Prout, H.T. (1990) Testing the robustness of the diagnostic overshadowing bias. *American Journal on Mental Retardation*, **95**, 204–214.

World Health Organization (1993) *The ICD-10 Classification of Mental and Behavioural Disorders. Diagnostic Criteria for Research*. Geneva: WHO.