Introduction

Rapid and pervasive changes have taken place in the past decade in providing support services to individuals who live with intellectual disabilities and mental illness. These services are most often provided by caregivers employed at specialized community agencies. However, family members and volunteers may also find themselves in the role of caregiver. Direct support workers are a diverse group in age, education, and previous experience. This is a large and growing group, yet many organizations have difficulty recruiting and maintaining highly qualified and trained personnel. Few teaching resources are available to those who educate and employ direct support workers.

In this open access book, we provide practical explanations of what caregivers can do when supporting individuals with both intellectual disabilities and mental illness (dual diagnosis). Achieving quality services and care depends critically on understanding client behaviours. This understanding can direct support workers and other caregivers in developing the knowledge, skills, and attitudes to do their job well. Such understanding can promote positive changes to the overall quality of the environment in which people live, work, and play. An inclusive environment contributes to the quality of life for people with dual diagnosis.

Our multidisciplinary authoring team draws on expertise from educators in psychiatric nursing, disability studies, and behavioural analysis. We balance this professional expertise with practical wisdom gleaned from working in the field and from consultations with over 20 institutions that educate and employ direct support workers. We provide easy-to-understand explanations of intellectual disabilities and mental illness, and concrete suggestions for evidence-informed support. Although this resource is geared to professionals and each chapter incorporates information from current studies to develop a topic area, each topic is summarized in text boxes emphasizing Key Points for Caregivers. This structure is designed to support a variety of curriculum planning, orientation, and training sessions. For those interested in more background knowledge, we include a comprehensive reference base. For those interested mainly in what to do for a specific problem, we provide summaries written in plain language.
In Chapter 1, Support Work: The Fundamentals, we introduce the foundational skills needed to work in the field of disability support. In Chapter 2, What’s in a Name?, we consider use of language associated with intellectual disability and using “people-first” language. In Chapter 3, An Overview of Mental Illness, we explain indicators associated with disorders of thinking, disorders of mood, and disorders of behaviour. In Chapter 4, Common Physical Concerns, we present factors that often impact the physical health of individuals with dual diagnosis. In Chapter 5, When the Problem Is Pain, we provide tools for assessing pain. In Chapter 6, Behaviour That Hurts, we explore self-injurious and aggressive behaviours. Finally, in Chapter 7, Sexuality, we discuss promoting healthy sexual expression.

We invite readers to dip into this book to find answers to their questions about why people with dual diagnosis might be acting in a particular way. We encourage educators and employers to share the suggestions in the Key Points for Caregivers with learners, either as handouts or other teaching materials. While everything caregivers need to know cannot be condensed into one resource, we provide foundational information that can make a difference to those who care about and for individuals with intellectual disabilities and mental illness.