Supporting Individuals with Intellectual Disabilities & Mental Illness

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What Caregivers Need to Know

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Dedication

To all those who support and care for individuals with both intellectual disabilities and mental illness.

Contents

Part I. Audio Compendium

Acknowledgments

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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.

CHAPTER 1: SUPPORT WORK: THE FUNDAMENTALS

Core principles

CHERYL CROCKER, PH.D. (REHABILITATION AND COMMUNITY STUDIES)

Introduction

Supporting individuals who have both an intellectual disability and a mental illness is rarely straightforward. Support work can be carried out by paid direct support workers, family members, or volunteers. Support can be offered in a variety of different environments including residential, vocational, and recreation and leisure. In all aspects of support work, fundamental knowledge from the field of disability studies can offer caregivers important direction. In this chapter, we identify guiding principles for support work, note historical struggles experienced by individuals with disabilities, and explain competencies expected of direct support workers.

Guiding Principles for Support Work

Four guiding principles are central to supporting people with disabilities. People with disabilities, just like people who do not have disabilities, have rights related to citizenship, individual control, equality and human rights, and universal design.

Citizenship means that people with disabilities have the same rights and responsibilities as people without disabilities. Socially constructed barriers, which prevent participation and discriminate against people with disabilities, must be eliminated.

Individual control signifies that people with disabilities must be involved in all stages of developing disability services and policies, and in all decision making that affects their lives. This is often missing in the way services have traditionally been provided, with services *directed by* professionals and *directed to* individuals. The shift to individual-controlled services has been a recent but very successful change.

Equality and human rights are pivotal in shifting approaches to providing service. In some countries, specific laws have been created to guarantee equal benefit and protection to all people. Laws prohibit discrimination based on disability. In some countries, legislation has been passed to promote employment equity. When employment equity laws are enforced, individuals cannot be denied employment for reasons related to ability. Employers are expected to make every reasonable effort to eliminate discrimination and barriers that have adverse impacts on people with disabilities.

Universal design requires that the environment be designed to be usable by people with various disabilities. Universal design highlights an important distinction between a disability and a handicap. An individual can have a disability but not experience a handicap. For example, an individual may have a physical disability and use a wheelchair. A ramp into a building would allow access to the building, removing a barrier that would handicap the individual with the physical disability. Universal design eliminates environmental barriers that handicap individuals who have a disability.

Guiding Principles for Support Work

Key Points for Caregivers
Guiding principles for support work state that people with disabilities have rights that relate to:

1. Citizenship, through freedom from discrimination
2. Individual control, through involvement in decisions related to their lives
3. Equality and human rights, through the benefits and protection of the law
4. Universal design, through barrier-free environments

“To deny people their human rights is to challenge their very humanity.”
— Nelson Mandela

Historical Struggles

People with disabilities have struggled for acceptance and equality for centuries. Historically, they have been ostracized. In ancient times, people with disabilities were often viewed as demonic or unique. Few survived and those who did were not typically part of the mainstream society. In Greek and Roman times, when able-bodied and able-minded soldiers were needed, people with disabilities were considered “defective” and exterminated. Later, in the Middle Ages, people with disabilities were positioned as servants or court jesters and fools; some were still put to death. The primary response to people with disabilities was ridicule for differences in physical appearance or behaviour.

The Renaissance brought an era of asylum for people with disabilities as the Catholic Church accepted them as wards of state. Although they were still cared for in isolation and without education, at least humane treatment was available. The Industrial Revolution introduced broader-based education, recognizing the need for a literate society and good workers. This vocational emphasis led to the emergence of sheltered workshops for people with disabilities.

The early 1900s introduced a biological emphasis to caregiving, and the primary service model was one of medical and institutional care. People with disabilities were warehoused in large congregate care facilities with a promise that training and education would be offered.

The mid-1900s shifted emphasis to the environment. Veterans returning from war spurred a rise in litigation and legislation to protect their rights to rehabilitation and employment. The civil rights movement in the 1950s and 1960s contributed to a much greater understanding of equality and rights, which trickled down to those with disabilities. The debilitating effects of institutionalization were acknowledged. Normalization, now known as *social role valorization*, became the widely held belief: that all individuals, regardless of any disability, should have as normal an education and living arrangement as possible (Wolfensberger, 1983, 2011).

Today, inclusion is the focus for most governments and services. In the United States, Rosa's Law (2010) has changed the way an intellectual disability is conceptualized. Rather than the older term *mental retardation*, the term *intellectual disability* is now used. The focus is on providing supports to individuals in the least restrictive environment possible.

Despite increasing attention to including individuals with disabilities in mainstream society, it would be a mistake to believe that persons with disabilities are part of their communities. Many still spend much of the day in environments that are not inclusive. All those who provide support to people with disabilities play a key role in discovering, organizing, and supporting them toward physical and social inclusion.

Historical Struggles

Key Points for Caregivers

Historically, people with disabilities were rejected, laughed at, and even put to death. Today, disability services emphasize the importance of including people with disabilities in communities. Social role valorization encourages communities to provide normal living, education, and employment opportunities whenever possible. Rosa's Law requires that the term *mental retardation* is replaced with the term *intellectual disability*.

Competencies Expected of Support Workers

What does it take to be informed and competent when supporting someone with a disability? A competency is an attribute, knowledge, skill, ability, or other characteristic that contributes to successful job performance. Competencies give rise to observable and measurable behaviours that contribute to individual success in an organization (e.g., teamwork and cooperation, communication). Direct support workers, regardless of the service that is provided, require competencies in working with others, assessing strengths and needs, planning and providing services, linking to resources, advocacy, documenting and report writing, professionalism and ethical behaviour, and individualizing support requirements.

Working with others is an expectation for direct support workers. The typical approach is to work collaboratively with others to plan and implement support plans. A multidisciplinary team might include professionals such as psychologists, occupational therapists, physical therapists, medical professionals, and social workers. Parents, guardians, and family members are also integral to the team. Teams promote coordination and communication, and add to relationships. They may also identify service gaps and raise awareness of strategies, resources, and approaches that might be of benefit in direct support. Teams are extremely valuable in furthering positive outcomes for clients who are in difficult or complex situations.

Assessing strengths and needs is a significant part of the direct support worker's job. The approach that is most favoured first identifies the talents, gifts, and skills of the individual being supported, with a view to using those to manage any needs the individual might have. An individualized strengths-based assessment then focuses on the complex interplay of risks and strengths among individual family members, the family as a unit, and the broader neighbourhood and environment. The individualized strengths-based approach is an overall philosophical view supported by policies and standards. It refers to practice methods and strategies that identify and draw upon the strengths of individuals, families, and communities.

Strengths-based practice requires a shift from a deficit approach, which emphasizes problems and pathology, to a positive approach (Rapp, Saleebey & Sullivan, 2005; Saleebey, 2006). A strengths-based approach values the capacity, skills, knowledge, connections, and potential in individuals and communities. Focusing on strengths does not mean ignoring challenges or spinning struggles into strengths. It does require that people work collaboratively.

Planning and providing services follows assessing strengths and needs. Most services have adopted a person-centred process to assist people with disabilities and their families to build their capacities and capabilities. This planning effort is typically a series of discussions or interactions among the person with a disability, his or her family, and other members of the multidisciplinary team.

The team assists the individual in developing a description that includes a preferred place to live, favourite people with whom to socialize, and preferred types of daily activities, including preferred jobs. This description is based on the individual's strengths, capabilities, preferences, lifestyle, and cultural background. The planning team decides what needs to be done, by whom, when, and how the individual is to work toward the preferred future. An individual program plan serves as a record of the decisions made by the planning team. This plan forms the foundation for the work of the direct service worker.

Linking to resources requires the direct support worker to have comprehensive knowledge of the community in which the supported individual lives. Community asset mapping is one approach to acquiring this knowledge. The community asset mapping process (Asset Based Community Development Institute, n.d.) is intended to initiate full mobilization of a community and its assets around an individual vision. It allows mapping of relationships with other organizations for funding, referrals, access to resources, joint service planning, or collaborative projects with contributed staff. Once a community's assets have been identified, the direct support worker is in a good position to begin linking the assets with the supported individual based on the individual's strengths and needs.

Advocacy in all its forms seeks to ensure that people, particularly those who are most vulnerable in society, are able to have their voice heard on issues that are important to them. Advocacy supports and enables people to access information and services, defend and promote their rights and responsibilities, and explore choices and options (Support Empower Advocate Promote, n.d.).

Documenting and report writing takes many forms. Most common is documenting history and needs, services, individual outcomes, and service information. Any documenting should be concise, accurate, current, meaningful, and consistent. Reports can include case notes, plans, assessment results, letters to parents, referrals to other community services, letters to funders, and reports to supervisors, to mention just a few. Documentation serves six primary functions: assessment and planning, service delivery, continuity and coordination of services, supervision, service evaluation, and accountability. In documentation, caution should be used with personal opinion and conclusions; defamatory and negative language should be avoided; over-documentation should be avoided; and the documentation should be directed to a specific audience.

Professionalism and ethical behaviour is a cornerstone for direct support worker practice. Professionalism is the conduct, aims, or qualities that characterize or mark a profession or professional person. In 1996 in the United States, the Council for Standards in Human Service Education adopted *Ethical Standards for Human Services Professionals*, which are a set of standards of conduct that human service professionals and educators consider in ethical and professional decision making (National Organization for Human Services, n.d.).

Section 1 of *Ethical Standards* is targeted to the human services professional and contains 37 statements in five responsibility areas: client, employer, community and society, colleagues, and the profession. Section 2, incorporating statements 38 to 54, outlines standards for human services educators. The National Organization for Human Services, a U.S. organization that publishes the standards, has done much to expand professional development opportunities, enhance communication, promote professional and organizational identity through certification, and advocate for a social policy agenda both in the United States and in other countries.

In Canada, the Developmental Services Human Resource Strategy is currently working on developing core competencies for direct support workers. With the intent of "positioning employment in the developmental services sector as a career of choice," the DSHRS continues to examine models for training and best practice that will strengthen professionalism among those who work in the field (DSHRS, n.d.). In Ontario, as part of quality assurance measures mandated in the Social Inclusion of Persons with Developmental Disabilities Act, 2008, developmental service agencies now have set standards to guide their policies and procedures (Government of Ontario, 2011).

Individualizing support requirements. Every person is different and may have individual support requirements that necessitate the support worker having specialized competencies. Often these competencies are specific to the environment, such as household management, budgeting, health and wellness, food safety, or job coaching. Other times they are skills that directly respond to individual needs and may include medication administration, crisis management, and non-violent crisis intervention or behaviour management. All individuals who are being supported will present with strengths, needs, and characteristics that require specialized knowledge.

Competencies Expected of Support Workers

Key Points for Caregivers

Caregivers who support individuals with disabilities, particularly caregivers who are employed as direct support workers, are expected to be competent and able to work with others to:

1. Assess the strengths and needs of clients
2. Plan and provide services
3. Link to resources
4. Advocate
5. Record information and write reports
6. Demonstrate professional and ethical behaviour
7. Tailor support requirements in relation to unique requirements of clients

Conclusion

This chapter has provided a snapshot of fundamental knowledge that caregivers can build on as they support individuals with disabilities. In the chapters that follow, we extend these fundamentals to explain support that is specific to individuals with both intellectual disabilities and mental illness.

Those who support people with disabilities are in a unique position to ensure that those individuals are included in their communities. To maximize the possibilities, it is important for caregivers to be guided by principles grounded in citizenship, individual control, equality and human rights, and universal design. Further, it is important to appreciate the historical struggles endured by people with disabilities. Knowing the competencies expected of support workers can assist caregivers, particularly those employed in direct support work positions, to develop and strengthen their skills.

Chapter Audio for Print

This chapter contains a number of short audio clips. If you are reading this in print, you can access the audio clips in this chapter by scanning this QR code with your mobile device. Alternatively, you can visit the book website at opentextbc.ca/caregivers and listen to all the audio clips.

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CHAPTER 2: WHAT'S IN A NAME?

The language of intellectual disability

JOHN SIMPSON R.P.N., M.ED. (SPECIAL EDUCATION)

Introduction

In act 2, scene 2 of William Shakespeare's *Romeo and Juliet*, Juliet declares: "What's in a name? That which we call a rose by any other name would smell as sweet." Unfortunately, Juliet's point of view doesn't extend to the world of disability, where names do matter (Wehmeyer, 2013). This is particularly true for the disability previously called *mental retardation*. The historical record shows that whenever new names have been introduced to identify and describe this disability, those names have eventually been abandoned because of the stigma they've acquired (Tassé, 2013). Like the names that preceded them, *mental retardation* and *mentally retarded* were clinical terms used to describe the presence of intellectual impairment. Like the other terms, they were eventually absorbed into popular language and used as insults to demean or belittle someone or someone's behaviour (Special Olympics Inc., 2014). Insults like "What a retard" and "That's so retarded" are common examples. While these insults are often aimed at individuals without disabilities, it is important to know that they have been formed from negative perceptions and attitudes about persons with *mental retardation.* They suggest that these persons are somehow defective, not quite human, or less valuable human beings.

In *The Cloak of Competence*, Robert Edgerton (1967) wrote, "to find oneself regarded as a mental retardate is to be burdened by a shattering stigma" (p. 205). Edgerton concluded, "persons cannot believe that they are mentally retarded and still maintain their self-esteem" (p. 207). Although Edgerton's terminology is now out of date, concern about the effects of stigma on the lives of people with intellectual impairment remains. It continues to be expressed in the words of those who have been hurt by the messages imbedded in the label *mentally retarded* and its common offshoots, *retarded* and *retard:*

- "I use to skip school just so I wouldn't have to hear kids use the R-word in the halls."
- "Just hearing the R-word hurts, even if you don't mean it that way."
- "You may be joking and calling your friend the R-word, but I still hear it."

- "When people say the R-word it really hurts my feelings and I feel bad about myself." (Special Olympics Inc., n.d.).

Attempts have been made to move away from the negative connotations and stereotypes associated with the terms *mental retardation* and *mentally retarded.* A variety of alternative names have emerged throughout the world and within individual countries (Ford, Acosta, & Sutcliffe, 2013). The world still struggles, however, to find a common language that is both respectful and effective in its ability to communicate to all stakeholders. Such language is needed so that proper identification occurs, needed supports are provided, and suitable environmental adjustments are made (Schalock & Luckasson, 2013).

In this chapter, we discuss the evolution of the clinical or official language that has been used to discuss intellectual impairment. We start with a discussion of the purpose of naming and then move to a description of names that have historically and more recently been applied. Guidelines for choosing an appropriate name are provided along with information on how intellectual impairment is currently viewed and diagnosed. Throughout the chapter, the impact of naming or labelling on people with intellectual impairment is discussed, and implications for caregivers are identified.

The Purpose of Naming

Naming refers to assigning a specific term or label to someone or something. In the field of disability, naming is the product of a systematic process of investigation known as diagnosis. Assigning a name, term, or label to an individual or the individual's disability is a powerful statement that can convey important messages about how that individual is perceived and valued, and how human relationships will take place (Davis, 2004; Luckasson & Reeve, 2001; Schalock, 2011).

In the field of disability, correctly identifying and naming the disability that a person experiences is important for a number of reasons. Naming enables needed services and supports to be deployed and provides the opportunity to remove physical and social barriers that prevent individuals from expressing their capabilities. Naming also makes funding available for needed services and supports. On a broader level, naming encourages research and communication about a particular disability. This can be important to improving conditions experienced by individuals with the disability. On the other hand, the negative connotations and stereotypes associated with names such as *mental retardation* and *mentally retarded* have caused some self-advocates to adopt the motto "Label Jars, Not People."

Historical Perspective

Before the 1900s, the word *idiot* was used throughout much of the world to describe a generally vague class of individuals who were not considered to be "normal." Membership in this class was often assigned simply because individuals were thought to look or walk "funny," or because they were poorly coordinated. Others were singled out because they did not speak, were not successful in school, or appeared to not act their age. The first broadly used term in North America was *feeble-minded*. The term became common in the early part of the 1900s and was eventually divided into diagnostic categories, or levels, of feeble-mindedness: moron, imbecile, and idiot. These approximated the later categories of mild, moderate, and severe/profound mental retardation, and were assigned on the basis of IQ score, after the IQ system was developed and popularized in the early 20th century (Walsh, 2002).

By the middle of the 20th century the terminology shifted, with terms such as *mental deficiency* and *mental defective* emerging in an attempt to counteract the negative connotations of *feeble-minded*. Over time, the idea that individuals were deficient and defective, and by extension not quite good enough, was replaced by the concept of *developmental rate*. This term suggested that persons with intellectual impairment were "slow" or developmentally arrested. The term *mental retardation* was used to represent this position.

In 1961, the American Association on Mental Deficiency (now the American Association on Intellectual and Developmental Disabilities or AAIDD) issued its new diagnostic and classification manual. It replaced the terms *moron, imbecile,* and *idiot* with *mild, moderate, severe,* and *profound mental retardation.* The category *borderline mental retardation* was also included, and referred to individuals who fell between 15 and 30 IQ points (between one and two standard deviations) below the average IQ of 100. In 1973, the borderline category was eliminated as IQ standards changed, so that people with IQs from 70 to 85 were no longer considered to have mental retardation. This meant that, overnight, the population of people theoretically considered to have mental retardation (at least on the basis of IQ score alone) decreased from about 16% to 3% of the general population. This reinforced the understanding that, to a large extent, mental retardation (although under new names) was and remains a socially constructed entity based on expectations of intellectual functioning. Those expectations can vary from time period to time period and from society to society, though individuals with significant disability are identifiable across all time periods and societies.

The Demise of Mental Retardation

Like the clinical labels *feeble-minded, idiot, imbecile, moron,* and *mental defective,* the term *mentally retarded* was quickly transformed into a common insult. The result was that well before the end of the 20th century, a challenge led by advocacy organizations deemed use of the label as no longer appropriate.

As acceptance weakened for the terms *mental retardation* and *mentally retarded,* a variety of terms arose to take their place. The following are some examples of replacement terms:

- ***Mental handicap or developmental handicap.*** While these terms were once popular, labels that include the word *handicap* or *handicapped* have largely been replaced with *disability*. Disabilities are impairments in functioning that can be physical or intellectual, or both in combination. Handicaps, on the other hand, are social or environmental obstacles imposed by society, institutions or individuals on persons with disabilities (Finkelstein, 1993). For example, the absence of a wheelchair ramp at the entrance to a building imposes a handicap on individuals who use wheelchairs. Likewise, failure to provide an individual's usual communication device imposes a handicap by preventing that individual from effectively communicating his or her needs, wants, thoughts, or interests in social situations. In addition, the word *handicap* echoes an earlier time when persons with disabilities were commonly required to beg on the street for survival—to literally extend their caps in hand for charitable donations (Darrow & White, 1997).
- ***Developmental disability.*** The term *developmental disability* is commonly used in Canada and some other countries to refer to intellectual impairment. However, in the United States, developmental disability is also viewed as an umbrella term that includes individuals who have intellectual or physical impairments, or a

combination of both, that occur during the developmental period (National Association of Councils on Developmental Disabilities, 2014). Examples of disabilities that fall under the heading of developmental disability are epilepsy, cerebral palsy, and autism, as well as intellectual impairment. When the population characteristics of all people with developmental disabilities are examined, only about one-quarter of them have an intellectual impairment sufficient to apply the former label *mental retardation* (Warren, 2000). The lack of specificity associated with the term developmental disability can lead to confusion when communicating with individuals or groups outside the jurisdictions that use the term.

- ***Mental disability.*** In its Vulnerable Persons Living with a Mental Disability Act, the Province of Manitoba (Manitoba, 2014) uses the term *mental disability* to refer to persons with intellectual impairment. This is a term, however, that some people in the mental health field also claim. One problem with this term is that it can cause confusion between the concepts of mental illness and intellectual impairment.
- ***Learning disability.*** In the United Kingdom, the term *learning disability* is used, having replaced the term *mental subnormality*. In North America, however, *learning disability* refers to persons with specific learning disabilities that do not impede general intellectual functioning. Dyslexia is an example of a specific learning disability. Many school districts, however, choose to apply a learning disability label to students with mild intellectual impairment to avoid the stigma associated with the label *mental retardation* (Warren, 2000).
- ***Developmental delay.*** The term *developmental delay* has been used when discussing intellectual impairment. However, while individuals with intellectual impairment commonly experience developmental delays, not all individuals with developmental delays experience intellectual impairment.

Guidelines for Choosing the Right Name

The name chosen to represent a disability has crucial implications for individuals to whom that name is applied. Therefore choose the name, term, or label with deliberate care. In the end, the name given to a disability should be able to meet the following standards (Luckasson & Reeve, as cited in Schalock & Luckasson, 2013):

- The name should be specific and refer to a single disability. It should allow the disability to be differentiated from other disabilities.
- The name should possess attributes that permit it to be accepted and used consistently by all stakeholders. Examples of stakeholders are individuals, families, service and support providers, professional organizations, advocacy groups, academics, researchers, government representatives, and policymakers.
- The name should effectively represent the current state of knowledge and be able to integrate new knowledge as it appears.
- The name should be functional in definition, diagnosis, classification, and planning of supports.
- The name should have the capacity to communicate important values that are held for the named group of people.

Intellectual Disability

The term *intellectual disability* is increasingly understood to meet the guidelines above (Schalock, 2011). It is a term commonly used by the research community and scholarly journals, and increasingly by the larger international community. Countries that have adopted this term include Australia, New Zealand, the Netherlands, Ireland, Israel, the United States, and the Scandinavian countries. In the United States, President George W. Bush signed an executive order in 2003 that renamed the President's Committee on Mental Retardation as the President's Committee for People with Intellectual Disabilities (Ford, Acosta, & Sutcliffe, 2013). And, in 2010, the U.S. Senate and the House of Representatives passed Rosa's Law (S 2781—111th Congress, 2009), changing references in federal legislation from *mental retardation* and *mentally retarded* to *intellectual disability* and *individual with intellectual disability*.

Advocacy organizations such as The Arc, Inclusion International, and Special Olympics use the term *intellectual disability*. The Canadian Association for Community Living and People First of Canada also use this term, although both *intellectual disability* and *developmental disability* are accepted and usage can vary by region. Community Living Ontario mentions that it adopted the term *intellectual disability* "largely to conform with growing national and international use of the term" (Community Living Ontario, 2014).

In addition to the countries and organizations just mentioned, the three principal sources for defining and diagnosing intellectual disability already use or will soon use the term *intellectual disability*. These sources are the 11th edition of the AAIDD's diagnostic manual; the fifth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5); and the 11th revision of the World Health Organization's *International Classification of Diseases* (ICD-11) (Tassé, 2013). The World Health Organization is expected to adopt the term in 2015. Of particular importance is that the ICD is used by 70% of the world's clinicians, with a similar percentage of services and supports receiving funding based on the diagnostic criteria specified in the ICD (Wehmeyer, 2013). To avoid use of the word *disability*, the term *disorders of intellectual development* has also been discussed.

People with Intellectual Disabilities: Using People-First Language

Advocates, self-advocates, and professional groups generally agree that labels should not act as personal nouns to represent individuals. For example, statements such as "Rashid is an epileptic" or "Maria is intellectually disabled" should be avoided. Individuals are much more than the disabilities they happen to experience. They are not defined by their disabilities. Instead, "people-first language" should be used to introduce the presence of disability. Statements such as "Rashid is a young man with (or, who has) epilepsy" or "Maria has Down Syndrome" or "Maria is a person who lives with intellectual disability" represent people-first language. Unless there is a reason to do so, mentioning an individual's disability is not even needed. Consider how you might describe someone who does not have a disability: for example, "Rani has a very dry sense of humour" or "Ampreet has such a warm and caring manner" or "Sarah has a mischievous streak."

This agreement that people-first language should frame conversations about intellectual disability extends to agreement that possessive language should be avoided when talking about conditions that are associated with intellectual or other disabilities. This means, for example, that the apostrophe and letter *s* should be removed when referring to Down's syndrome. *Down syndrome* is, therefore, the terminology of choice (although some self-advocates prefer to say that they have *Up syndrome*). This avoids the paternalism in naming conditions, disorders, and diseases for the persons who first identified them.

What Is Intellectual Disability?

Intellectual disability affects general learning, so an individual with an intellectual disability can be expected to take longer to learn and to encounter a lower learning ceiling. How low the learning ceiling is depends on the severity of disability, exposure to learning opportunities, and availability of supports. While intellectual disability places limits on an individual's ability to understand and use new or complex information, the disability is not presented in isolation from the surrounding environment. Disability and individual functioning then, is "always an interaction between features of the person and features of the overall context in which the person lives" (World Health Organization, 2002). Equally important is that each person's features include strengths as well as limitations and that these strengths can contribute to effective functioning within environments. This has important implications for the person-centred planning process.

From a diagnostic point of view, the AAIDD states, "Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical skills. This disability originates before age 18" (Schalock et al., 2010, p.1). Intellectual functioning is determined by IQ testing, with an IQ below 70 to 75 establishing eligibility for a diagnosis of intellectual disability. The five-point IQ range is recognition that IQs are not perfect measures, and that a score of 70 on a single IQ test actually means that the true score is likely plus or minus 5 IQ points, somewhere between 64 and 76. *Adaptive behaviour* refers to behaviours or skills that individuals acquire as they grow and develop. These lead to increasing levels of independence and social responsibility within the individual's culture and community. These behaviours or skills are referenced to norms and take into account the expectations of particular societies for individuals at different ages. In the context of intellectual disability, the presence or absence of limitations in adaptive behaviour is determined by outcomes achieved on adaptive behaviour assessments. Conceptual, social, and practical skills are categories of adaptive behaviour. They include skills in language, reasoning, writing, social judgment, interpersonal communication, personal and domestic care, money management, and job responsibilities (American Psychiatric Association, 2013).

In essence, adaptive behaviour is the outward expression of intellectual functioning. As a consequence, diagnosis of intellectual disability depends on measurable limitations in adaptive behaviour as much as it depends on limitations in IQ outcomes (see Table 2.1). This suggests that there is no reason to apply a label of intellectual disability to someone if that person is able to function satisfactorily within his or her environment, regardless of IQ score.

Table 2.1 Diagnosis of intellectual disability

	IQ Above 70–75	**IQ Below 70–75**
No significant adaptive behaviour limitations	NO intellectual disability	NO intellectual disability
Significant adaptive behaviour limitations	NO intellectual disability	YES intellectual disability *Plus: occurs before age 18

Classification

Like people everywhere, people with intellectual disability are not all the same. The range includes individuals with "few, if any, self-preservation skills who require round-the-clock supports, to individuals who differ very little from the general population" (Walsh, 2002, p. 73). Classification systems are in part recognition that the name or label *intellectual disability* is an inadequate description of how the disability is expressed by each individual. This is reflected in classification categories that differentiate either levels of intellectual disability or intensities of support needs.

Levels of intellectual disability are specified by two of the three major diagnosis and classification systems, the DSM-5 and the ICD-10 (soon to be ICD-11). When an individual is diagnosed with intellectual disability, he or she is assigned a level of mild, moderate, severe, or profound intellectual disability. In contrast, the AAIDD chooses to assess for support needs across a variety of everyday domains or areas of functioning. Instead of focusing on limitations or individual deficits that are invariably associated with levels of intellectual disability ("He can't do that. … he's severely retarded!"), this shift in thinking takes as its starting point "considerations of what it will take to enable people to function successfully in typical environments" (Wehmeyer, 2013, p. 124).

Intensities of support needs are classified as *intermittent, limited, extensive,* and *pervasive*. For any individual, these may vary from domain to domain and from time to time, depending on events and circumstances. Intensities of support needs are described as follows:

- ***Intermittent***. Support is periodic and of short duration. An example is support during lifespan transitions such as job loss, family member loss, or an acute medical crisis. During the time that it is given, this support may be of high or low intensity.
- ***Limited.*** Support is more consistent but not intense. An example of this support is time-limited employment training.
- ***Extensive.*** Regular support (e.g., daily) is provided in some environments. For example, long-term support may be required in the home or work environments.
- ***Pervasive.*** Intense and constant supports are provided in all environments. These supports have life-sustaining potential, and typically involve more staff members and intrusiveness than extensive or limited supports. Keep in mind, however, that intermittent supports may be high intensity during the time that they are provided (Luckasson et al., 2002).

The Impact of Names Beyond the Hurt Feelings: Implications for Service and Support

As has been stressed throughout this chapter, the names or labels that we use to talk about people with disabilities reveal something important about the way society views them. As a result, the names or labels (and the perceptions that underlie them) have an impact on how we interact with persons with disability. For example, when adults with intellectual disabilities are viewed as "eternal children" and referred to as "kids," as was the case within many large, traditional institutional settings, their possibilities become limited by the expectations that we commonly hold for children. In practice, this has meant that adults with intellectual disabilities have been talked to in a childlike manner and have been required to participate in child-oriented activities. This means that they are not provided with opportunities to develop and prosper beyond the confines of the restrictive points of views of others. By implication, people with intellectual disabilities will never achieve the status of a valued adult.

From the point of view of service and support systems, negative impressions and expectations associated with disability-related names or labels sometimes mean that labelled individuals do not received services that would be given to non-labelled individuals. For example, an impatient mental health professional may dismiss concerns of a support provider about a person with intellectual disabilities and a suspected mental health disturbance, with a comment such as "What do you expect? She's mentally retarded!" Reiss and colleagues (1982) refer to this practice as "diagnostic overshadowing"*:* the tendency to diminish the importance of unexpected or symptomatic behaviour as merely representative of intellectual disability. This form of stereotyping and prejudice is demeaning. In part, it has contributed to the comparatively poorer health and shorter lifespan experienced by people with intellectual disabilities. It is important, therefore, for service and support providers to confront their own misconceptions and prejudices, should they exist. Other people's misconceptions and prejudices might then be corrected for the well-being of people with intellectual disabilities.

When service and support providers understand the impact of names and language and the attitudes that support them, they are better equipped to understand appropriate names and language to use, as well as language to avoid.

The Impact of Names Beyond the Hurt Feelings: Implications for Service and Support

… Language to AVOID

Key Points for Caregivers

1. Avoid describing people with intellectual disabilities as all the same. For example, avoid using the word *the*, as in *the intellectually disabled*, when talking about individuals with intellectual disabilities. This form of description treats people with disabilities as objects and interferes with recognizing each person's uniqueness.
2. Avoid referring to individuals as particularly remarkable or interesting because they are people with intellectual disabilities. Language that sets individuals or groups apart as somehow special or unusual because of their disability actually reduces their value as human beings. This includes praising someone as "brave" or "courageous," simply because that person has an impairment.
3. Avoid using language that expresses pity for a person with disability or for their family. For example, avoid comments such as "It's just so unfair (or "What a shame" or "What a pity" or "How awful") that your son has to live with such a disability."
4. Avoid polite terms or language that is vague and confusing. Though some terms sound sensitive, such as *differently abled* or *developmentally challenged*, those terms only indicate that a disability exists. They do not actually identify the disability.
5. Avoid using language that labels a person with an intellectual disability as someone who suffers

from, is a victim of, or is afflicted with the disability. These descriptions give negative suggestions about the person with the disability.

6. Avoid using language that describes people with intellectual disabilities as having lower status. For example, by describing people without disabilities as “normal,” individuals with disabilities are suggested to be “abnormal.” This can suggest that people with disability are not good enough to belong to the preferred group, normal.

The Impact of Names Beyond the Hurt Feelings: Implications for Service and Support

… Language To USE

Key Points for Caregivers

1. Use language that is respectful, caring, and kind, and that communicates that the person is valued.
2. Use language that is appropriate to age and culture. For example, when meeting an older adult, a common custom may be to use a greeting such as “I am pleased to meet you Mr. Dodge. May I call you Henry?” rather than presuming that Mr. Dodge can be called Henry simply because he has intellectual disability.
3. Use language that is preferred by the person living with the disability. For example, members of the People First self-advocacy organization in Great Britain prefer to say that they experience learning difficulties instead of saying that they have intellectual disability, or a learning disability.
4. Use the person’s name and discuss issues in the same way that you would discuss issues when talking with or talking about someone who does not live with intellectual disability.
5. Treat each person as a person first, and with the understanding that using diagnostic labels is required only rarely and only in highly specific situations.

Conclusion

In this chapter we have discussed the evolution of language used to talk about people with intellectual disabilities. The value of naming has been described, as have been the negative consequences associated with names that were historically applied to people with intellectual disabilities. Guidelines for choosing an appropriate name have been listed, with the term *intellectual disability* identified as the name or label that has widespread national and international use and appears to meet standards for selection. The importance of using people-first language to frame discussion has been emphasized, stressing that the labels and diagnoses assigned to individuals do not define individuals.

This chapter has included a definition of intellectual disability, along with a description of the criteria used to diagnose intellectual disabilities. The value of classifying disability according to intensities of support needs, rather than on the basis of level of disability, has been described. Finally, implications for service and support providers have been discussed from the point of view of the impact that names and language can have on people with intellectual disabilities.

Chapter Audio for Print

This chapter contains a number of short audio clips. If you are reading this in print, you can access the audio clips in this chapter by scanning this QR code with your mobile device. Alternatively, you can visit the book website at opentextbc.ca/caregivers and listen to all the audio clips.

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CHAPTER 3: AN OVERVIEW OF MENTAL ILLNESS

Common psychiatric disorders

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Introduction

People who are mentally ill can have considerable difficulty with their thinking, their mood, or their behaviour. Mental illness is not the same as experiencing normal stress and sadness. One main difference is that mental illness causes significant distress and impairs functioning, making it difficult to cope with the demands of everyday life (Canadian Mental Health Association CMHA, n.d; Mental Health Foundation, n.d; Mental Health Foundation of Australia, n.d; National Alliance on Mental Health, n.d; Public Health Agency of Canada PHAC, n.d.). In other words, when people are mentally ill, they can't manage activities of daily living, work effectively, or maintain relationships. Their overwhelming distress is not just a reaction to daily events, and they are not behaving that way on purpose. Just like a physical illness, when a mental illness is not recognized and treated, it can worsen and will last for an unnecessarily long time.

It is not easy to recognize when the distress experienced by a person with an intellectual disability is actually a symptom of mental illness. The stigma associated with mental illness makes most people reluctant to talk about their experiences of having strange thoughts or deep sadness. For individuals with intellectual disabilities who already struggle to find the right words to express themselves, talking about their unusual experiences can be overwhelming.

When health professionals diagnose psychiatric disorders, they rely on information obtained during interviews with clients. However, clients with intellectual disabilities may not have the language or memory skills needed to explain what has been happening. When these clients have had only limited opportunities to socialize with others, they may be unsure about whether their experiences are “normal” or not. People in their lives may have ignored their symptoms of mental illness because they believed these symptoms were simply part of the disability.

In this chapter, we describe indicators of mental illness in three key areas: disorders of thinking, disorders of mood, and disorders of behaviour. Although only qualified clinicians can diagnose psychiatric disorders in individuals with disabilities, all those who care for them can help report the kinds of indicators that could be symptoms of mental illness. The chapter begins with a brief background of mental health care; identifies key indicators associated with disorders of thinking, mood, and behaviour; and emphasizes relevant observations that caregivers must report.

Background of Mental Health Care

History

Until the 17th century, most people who were considered to be insane were viewed as sinful, weak, or possessed by demons. Cast out of most societies, they were incarcerated in jails or poorhouses. Although asylums or mental hospitals were eventually created to house people with mental illness, early treatment approaches were crude.

Individuals with intellectual disabilities, traditionally referred to as *mentally retarded*, were often housed in these asylums as well. Distinctions between insanity and retardation were not always clear. Those named as *mildly retarded* were believed to be worry-free and therefore mentally healthy. Those with the label *severely retarded* were believed to be unable to express feelings and therefore not able to experience emotional distress (Werges, 2007). Inmates in the asylums were not viewed as people with an illness; rather, they were considered untreatable and were punished for any unusual behaviour.

By the early 20th century, mental health care became viewed as a public responsibility, and insane asylums were replaced by hospitals providing medical care. During the 1950s and 1960s, research led to an increased understanding of mental illness, and specific psychiatric disorders and associated treatments were identified. As it became clear that psychosocial factors can contribute to mental illness, psychiatric disorders became more normalized, or viewed as conditions that could happen to anyone. However, advances in understanding mental illness in individuals with intellectual disabilities occurred at a much slower pace. Separate institutions were established for these individuals and unusual behaviour was still not always considered a symptom of mental illness.

By the 1970s, a movement toward de-institutionalizing people with mental illness began to grow. Admissions to hospital beds were decreased and community agencies were expected to provide care. Unfortunately, for many individuals the expected help from community agencies still remains elusive. Today numerous individuals with mental illness find refuge only in jails and homeless shelters. Those with severe and persistent mental illness present in general hospital emergency rooms and yet, if admitted at all, may be discharged within days without having received the help they need. These shorter hospital stays and limited community supports have made it even more difficult to understand the unique needs of those diagnosed with both intellectual disability and mental illness (dually diagnosed).

Reversing the Trend

In an effort to reverse the international trend of neglecting health services and care for people who are mentally ill, the World Health Organization (2013) presented their *Mental Health Action Plan 2013–2020*, calling for governments to find better ways to recognize mental illness and improve treatment. Similarly, the National Institutes of Mental Health (2008) in the United States, the Mental Health Commission of Canada (2012), the Mental Health Council of Australia (n.d.), and the government of the United Kingdom (Her Majesty’s Government, 2011) all developed strategic plans to improve mental health. It is hoped that these strategic plans will be the start of changing society's perceptions of mental illness.

Diagnosis

Throughout history, the process of classifying different types of mental illness and finding ways to consistently explain people's unusual experiences has taken many forms. Today, psychiatrists and clinicians use two manuals to classify and diagnose psychiatric disorders. The first is the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5, American Psychiatric Association, 2013). The DSM was first published in 1952 and has been revised several times. The DSM-5 is a reference manual that outlines a set of criteria that health professionals can use to provide consistent treatment of mental illness, including symptoms, descriptions, markers, and treatments of mental disorders.

The second is the *International Statistical Classification of Diseases and Related Health Problems, 10th Revision* (ICD-10, World Health Organization, 2010). This manual uses a system of coding created by the World Health Organization to track health interventions. More than 40% of people with intellectual disabilities are dually diagnosed with a psychiatric disorder (Cooper et al., 2007; Lunsky, Klein-Geltink, & Yates, 2013).

For clinicians to use diagnostic manuals and other assessment tools to accurately diagnose psychiatric disorders, they need in-depth descriptions of how clients are thinking, what their mood is like, and how they are behaving. Knowing that people with intellectual disabilities may not be able to provide all the information needed, their caregivers can contribute by sharing relevant observations. In the following sections, we highlight indicators known to be associated with common psychiatric disorders.

Indicators Associated with Disorders of Thinking

Schizophrenia

According to the World Fellowship of Schizophrenia and Allied Disorders (n.d.), schizophrenia strikes 1% of the world's population. Individuals with intellectual disabilities are affected by schizophrenia more frequently than the general population, and they are more likely to be hospitalized for their symptoms (Balogh et al., 2010). Schizophrenia affects people from all walks of life and usually first appears between the ages of 15 and 30. Not everyone will experience the same symptoms, but some symptoms are common to many, such as withdrawing, hearing voices, talking to oneself, seeing things that are not there, neglecting personal hygiene, and showing low energy.

Schizophrenia refers to a group of severe, disabling psychiatric disorders marked by withdrawal from reality, illogical thinking, delusions (fixed false beliefs that cannot be changed through reasoning), hallucinations (hearing, seeing, smelling, tasting, or feeling touched by things that are not there), and flat affect (lack of observable expressions of emotions, monotone voice, expressionless face, immobile body).

Distinguishing between positive or hard, and negative or soft, symptoms is particularly important with schizophrenia. Notice that in this context, the word *positive* is not the same as *good*. Rather, positive symptoms are psychotic and demonstrate how the individual has lost touch with reality. Positive symptoms are those that do exist but should not exist, such as delusions, hallucinations, and disorganized thinking and behaviour. Delusions fall into several categories. An individual with a persecutory delusion may believe he is being tormented, followed, tricked, or spied on. An individual with a grandiose delusion may believe she has special powers. An individual with a reference delusion may believe that passages in books, newspapers, television shows, song lyrics, or other environmental cues are directed to him. In delusions of thought withdrawal or thought insertion, the individual believes others are reading her mind, her thoughts are being transmitted to others, or outside forces are imposing their thoughts or impulses on her.

In contrast, negative symptoms are those characteristics that should be there but are lacking. For example, negative symptoms include apathy (lack of interest in people, things, and activities), lack of motivation, blunted affect (reduced displays of emotion), poverty of speech (brief terse replies to questions that lack content), anhedonia (lack of interest in activities once enjoyed), and asociality (avoidance of relationships). Keep in mind that the inability to show emotion associated with a blunted affect does not reflect an inability to feel emotion. Similarly, it is helpful to understand that withdrawing from others is a coping mechanism for an individual with schizophrenia and not a rejection of those who initiate contact.

Indicators Associated with Disorders of Thinking: Schizophrenia

Key Points for Caregivers

1. With schizophrenia, all those who care for verbal clients must try to **know the content of any hallucination or delusion** their client is experiencing or has experienced. A typical hallucination might involve a deep, loud commanding male voice repeatedly telling a client that he or she is “worthless and must die.” Caregivers are expected to pose a clear question, such as “Are you hearing voices right now?” when clients are talking to themselves.

2. Caregivers of non-verbal clients must try to **determine if hallucinations or delusions are occurring**. Indicators of hallucinations include:

    a. Staring to the side and nodding and making hand motions as though listening to a conversation others do not hear

    b. Physically attacking an unseen other person

    c. Staring with an angry or frightened expression at strangers or well-liked companions in a situation that does not require those emotions

    d. Covering the eyes or ears as if to protect oneself, when threats are not present

    e. Frowning as though something smelled or tasted foul

    f. Dressing in protective ways such as wrapping on extra scarves or blankets when the weather does not require it

3. The nature of schizophrenia prevents the client from understanding that the voices or other hallucinations or delusions are not real. The only treatment that is effective in decreasing the thought changes in schizophrenia is antipsychotic medication. Without medication, trying to orient clients to reality can bring on profound anxiety and even aggressive actions. Caregivers must **know what psychiatric medications have been prescribed**.

4. The major side effects of psychiatric medication are a further challenge to treating schizophrenia. Hal-

lucinations and delusions often include the belief that antipsychotic medication is *poison*. In response to this belief, psychotic clients frequently pretend to swallow pills, or *cheek*. Given this unchangeable reluctance to swallowing pills, clients often receive long-acting antipsychotic medications intramuscularly during monthly clinic visits. However, caregivers must **always watch clients swallow their psychiatric medications**.

Psychosis

Traditionally, explanations of psychiatric disorders were introduced as conditions considered either psychotic (not in touch with reality, such as schizophrenia) or neurotic (in touch with reality but deeply troubled, such as anxiety). However, as research extends knowledge within the field, the experience of psychosis is now understood to be associated with a number of non-psychiatric conditions. Both children and adults with intellectual disabilities may engage in self-talk and conversations with imaginary friends. These fantasy conversations can appear as though they are indicators of psychosis such as delusions or hallucinations. When clients are able to indicate some awareness that these conversations are imaginary, and when clients seem to be directing or controlling them, they are not considered indicators of psychosis. Psychotic symptoms may be present with clients who are dehydrated, experiencing seizure disorders, on new medications, or taking street drugs.

Indicators Associated with Disorders of Thinking: Psychosis

Key Points for Caregivers

1. With psychosis, determine whether clients know that **fantasy conversations** are not real.
2. Rule out **dehydration**, particularly in clients who are elderly.
3. Ask whether the client has been having seizures or has a **seizure disorder**.
4. Note whether a **new medication** or new medical condition is present.
5. Document any **street drug use,** as many drugs induce psychotic-like behaviour.

Dementia

Dementia is not a specific disease; rather, it is a group of symptoms that affect thinking and social abilities enough to seriously interfere with daily functioning (Alzheimer's Association, n.d.). Dementia occurs at a higher rate in people with intellectual disabilities than it does in the general population (Janicki & Dalton, 2000; Jokien et al., 2013; National Task Group on Intellectual Disabilities and Dementia Practices, 2013; Shooshtari et al., 2011). Adults with Down syndrome are particularly susceptible to Alzheimer's disease as they approach middle age (Wilkinson & Janicki, n.d.).

Progressive memory loss that occurs over a period of time is often associated with Alzheimer's disease and other dementias. However, in clients with intellectual disabilities, indicators may be seen first in symptoms of physical deterioration. Previously mastered skills with daily living may become a problem. Clients may have difficulty with their sight, hearing, and speech. They may remain inactive for long periods of time. Their gait (the way they walk) may change. They may lose their sense of balance and fall frequently. Seizures may occur in those previously unaffected. As their condition worsens, clients find it very hard to learn new information. They become disoriented and no longer recognize caregivers and family. During all stages of dementia, feelings of intense anxiety and fearfulness are common.

When memory loss occurs, most people feel frightened, frustrated, and angry. When they can't answer a question they once could, they may confabulate (unintentionally make up) a reply. Keep in mind that confabulating is not lying and people are not deliberately being deceitful.

Sundowning, or sundown syndrome, is expected in clients with dementia. In this state, clients show increased agitation, restlessness, and confusion in the late afternoon, evening, and night (Khachiyants et al., 2011). At sundown, clients may become more anxious and disoriented. They may pace, wander, and even become aggressive and yell or scream as the day comes to a close. Clients can be more difficult to redirect at this time. It is important to note that dark, quiet rooms may be frightening to sundowning clients.

Indicators Associated with Disorders of Thinking: Dementia

Key Points for Caregivers

1. **Keep records of changes in behaviour and loss of previous abilities.** This is especially important to health care workers diagnosing dementia. Therefore, maintaining clear records of how clients function throughout their adult life is useful. These records can be formal medical charts obtained from physicians, or they can be informal records obtained from family members or clients themselves. Scrapbooks, photo albums, video home movies, and audio recordings will illustrate how clients spoke, moved, and responded when they were well and healthy. Comparing a previous picture, audio, or video with a current cell phone capture of a client can clarify changes that are happening.
2. **Record specific examples of physical weakening, particularly in speaking and walking.** For example, identify how a client's gait (or how they walk) is changing. Keep a record of any falls, stumbles, or times when clients seem to lose their balance.
3. **Prepare for and seek medical help immediately if seizures occur.** A seizure in someone previously unaffected and that is not part of a medical condition can indicate dementia.
4. **Understand and identify how often confabulation answers are occurring. *Confabulation* means making up answers without intending to lie.** Knowing that clients with dementia are not lying or making things up on purpose can help caregivers understand that this behaviour is part of a psychiatric disorder and not acting-out behaviour.
5. **Understand and identify how often sundowning is occurring. *Sundowning* means increased agitation in the evening.** Clients may seem to be expressing anger by behaviours such as screaming and yelling, but it is important to understand that this behaviour is likely a response to an intense and

constant inner fear that clients are unable to escape.

6. **Create and communicate supports that help memory lapses.** People with dementia are forgetful, get lost, and can have difficulty recognizing friends, family, and staff. Whenever possible, create cues to help with memory loss, such as calendars of events, photo collections, or scrapbooks. Ensure that these cues are consistent and that as many people as possible in the client's life know about them.

Differentiating between Dementia, Delirium, Dehydration, and Depression

Dementia should not be confused with delirium, dehydration, or depression, even though all these conditions can leave clients feeling confused. Dementia, as explained above, is a progressive disorder where people become confused over a long period of time. Delirium is a disorder where people become confused quite suddenly and it can be caused by a medical condition such as an infection. Dehydration is also a condition where people become confused quite suddenly; it is caused by not taking in enough fluids. Depression, as explained in the following section, is a mood disorder where deep sadness can make people seem as though they are confused.

Indicators Associated with Disorders of Mood

Depression

Depression is a mood disorder where people feel very sad even when things are going well. Mood disorders are disturbances in the regulation of mood, behaviour, and affect that go beyond the normal ups and downs that most people experience. Mood refers to a pervading feeling (a feeling that is there all the time) that lasts for more than two weeks. With depression, a person's mood becomes so intense that others just cannot help to cheer them up. Medications, such as antidespressant drugs, are needed to treat depression when it is serious enough to be diagnosed as a psychiatric disorder.

One out of every five people experiences depression during his or her life, and the rate of depression among people with intellectual disabilities is significantly higher (Shooshtari et al., 2011). Many people with mood disorders have coexisting mental and physical disorders. For example, about half of those with a depressive disorder also suffer from an anxiety disorder.

Health care providers rely heavily on descriptions of clients' affect to diagnose depression. *Affect* refers to the outward expression of emotion on people's faces, their bodies, and the way they speak. People cannot usually control their affect. Even when people who are depressed try to smile, their affect may seem "flat "or without any real emotion. People who are depressed sometimes have a restricted affect where they do not seem to show any emotion at all. They may also have an inappropriate affect where the emotions that they show do not match the content of what they are saying; for example, laughing when describing a loved one's recent death. Affect can also be labile (change quickly) with no apparent connection to events in the environment.

Types of depression include major or unipolar depression, dysthymia, and bipolar affective disorder.

Major or unipolar depression is a mood disturbance in which the major symptoms—depressed mood and loss of interest or pleasure in all or almost all activities—occur daily for at least two weeks and severely incapacitate a person's usual ability to function. In extreme cases, psychosis can be present in depressive disorders. When people with intellectual disabilities experience major depression, they may try to stay in bed all day, become mute, eat too little or too much, and refuse to wash or even use the toilet.

Major or unipolar depression can be further described as *agitated* or *retarded*. An agitated depression is accompanied by psychomotor agitation such as restlessness, sobbing, and excessive talking. A retarded depression is accompanied by slowed or absent psychomotor activity.

Depressive disorders can be exogenous or endogenous. *Exogenous* means that the illness follows a clearly defined stress such as a death or unexpected change in living arrangements. *Endogenous* means that no obvious stressors exist. It is important to emphasize that an endogenous major depression is NOT a reaction to loss. A lively approach by caregivers or others seeking to cheer up clients is ineffective.

Dysthymia is a mood disorder where people do feel sad for most of the day but they can still function, particularly toward the end of the day. Dysthymia can last for years and often goes unrecognized.

Bipolar affective disorder, formerly known as manic depressive illness, is marked by serious mood swings. Typically, clients experience extreme highs (mania or hypomania) alternating with extreme lows (depression). People feel normal only in the periods between the highs and lows. For some people, the cycles occur so rapidly that they hardly ever feel a sense of control over their mood swings.

In the manic phase of their bipolar illness, clients demonstrate grandiosity (feeling grand and better than others), jocularity (joking more than is appropriate), flight of ideas (rapidly skipping from one idea to the next in conversation), and decreased impulse control. They may go several days without sleeping at all. They may demonstrate problematic social behaviours such as aggression, property destruction, fecal smearing, stripping off clothing, and urinating in inappropriate places (McKee et al., 2004). People with intellectual disabilities may demonstrate grandiosity by believing they can drive a car when they cannot, for example. They may demonstrate decreased impulse control by spending all their money instead of saving in a planned way. They may engage in risky sexual activity that results in pregnancy or sexually transmitted diseases. They can be expected to neglect their needs to eat well, to sleep adequately, and to care for themselves.

Suicide

Thinking about suicide is common in people who are depressed. Caregivers must always ask if clients have ever thought about hurting or killing themselves, or otherwise try to assess clients who are or may be depressed. People who are thinking about killing themselves may engage in risky behaviour, such as walking into traffic with their eyes closed. They may seem preoccupied with the topics of death, of others who have died, and of funerals. It is important to ask verbal clients three questions:

1. Have you considered taking your own life?
2. How do you plan to commit suicide?
3. What stops you?

In clients with little or no ability to express their thoughts of suicide, unusual behaviours may be associated with a wish to stop unrelenting mental distress by dying. A behaviour may not actually seem potentially lethal, such as manual self-strangulation. However, when people intend to die and believe what they are doing will cause death, their attempts to kill themselves must be taken seriously (Byrne, Hurley, and James, 2007)

It is important to emphasize that suicide gestures and attempts are sometimes made when a client appears to be getting better and caregivers believe that the depression has lifted. However, a brighter and more cheerful affect may signify the client's feelings of relief. The client's feelings about wanting to die may not have changed. In fact, when people begin to feel their energy returning, they are more able to follow through on their decision to end their life. Similarly, given that antidepressant medications can be expected to take 7 to 21 days to become fully effective, they may actually provide clients with the increase in energy needed to act on their suicidal ideas.

A further key consideration is to ensure that any items that might be used for self-harm (razors, knives, pills, belts, or cords) on a client's person or in their environment are taken away. Keeping clients who are depressed and suicidal safe requires consistent monitoring. Increased caregiver time, attention, and presence are needed.

Vegetative shift is a term used by mental health professionals to describe problems associated with depressive disorders. A vegetative shift occurs when vegetative signs shift or change. Critical vegetative signs include affect, energy, pleasure, appetite, sleep, and thoughts of suicide. A memory aid for indicators of vegetative shift is "A E P A S S."

Indicators Associated with Disorders of Mood: Vegetative Shift

Key Points for Caregivers

Vegetative shift is a term used by mental health professionals to describe problems associated with depressive disorders. A vegetative shift occurs when vegetative signs shift or change. Critical vegetative signs include affect, energy, pleasure, appetite, sleep, and thoughts of suicide. A memory aid for indicators of vegetative shift is "A E P A S S": Affect, Energy, Pleasure, Appetite, Sleep, Suicide.

Use the "A E P A S S" memory aid to document a shift in vegetative signs.

- **A–an Affect of sadness and poor concentration.** Identify sad facial, postural, and emotional responses that last for weeks at a time and do not seem to fit the context. Sadness in clients may or may not be a response to something that has happened. Clients may show their depression through crying, becoming withdrawn and non-responsive, or becoming agitated and verbally and physically aggressive.
- **E–Energy loss and fatigue.** Write down the number of times clients are refusing to leave their beds, take care of activities of daily living such as bathing and dressing, and attend work or leisure activities. Include times when either constipation or incontinence occurs in relation to lacking the energy to go to the bathroom. Include the number of hours clients spend sitting or lying down for long periods of time just watching TV or doing nothing.
- **P–Pleasure or interest.** Notice whether clients are no longer taking pleasure in activities they once

enjoyed. Notice also when clients with bipolar disorder are cycling into a manic or hyperactive state, when they may carry out pleasurable activities impulsively. In particular, monitor reckless behaviour in spending money and sexual activity.

- **A–Appetite changes.** Appetite can increase or decrease in depressive disorders. Carefully record client weight and identify any gains or losses. Tantrums at meals, and stealing or hoarding food for constant nibbling, can reflect a need to soothe the emotional distress of depression. In contrast, refusing to take the time to eat can reflect the hyperactivity associated with a manic state.
- **S–Sleep disturbances.** Keep a record of the number of hours clients sleep each night, including the time they go to bed, the number of times they get up in the night, and the time they wake up. Difficulty falling asleep can be an indicator of anxiety. Waking up early can be an indicator of depression. Sleeping in late can be a response to dysthymia, where people feel sad in the morning but then feel better as the day progresses. Remaining in bed and sleeping or dozing for long periods of time during both night and day can be a way of withdrawing that is often associated with depression. In contrast, going to bed late, getting up frequently in the night, and getting out of bed early can indicate a pattern of hyperactivity associated with a manic state.
- **S–Suicidal thinking.** Ask verbal clients if they have thought about taking their own life, if they have a plan to do so, and what (if anything) stops them. Assess if clients seem to speak often about death when such discussions are out of context. Probe whether the thinking behind self-harming behaviour is related to an intent to commit suicide. **Important: Remove any objects that could be used for self-harm.**

Anxiety

Anxiety disorders are a group of conditions marked by pathological or extreme anxiety or dread. People with anxiety experience disturbances of mood, behaviour, and most systems in the body, making them unable to continue with everyday activities. Many feel anxious most of the time for no apparent reason.

Anxiety is different from fear. Fear is a response to an event or object that a person is aware of. The psychiatric disorder of anxiety occurs when the intensity and duration of anxiety does not match the potential for harm or threat to the affected person. Symptoms of anxiety disorders often include aches and pains throughout the body, and treating these can distract caregivers from recognizing anxiety as a cause of the physical pain.

People with intellectual disabilities struggle with anxiety more often than the general population. In part, this may be due to slightly different brain structures, limited expressive language abilities, and difficulty understanding social situations, which seem unpredictable and scary (Cooray & Bakala, 2005). Anxiety can be expressed with physical symptoms such as stomach aches, headaches, increased heart rate or pounding heart, feeling startled easily, trembling, sweating, and difficulty swallowing. It can be expressed behaviourally through increased agitation, crying, repeating comments about feeling afraid, withdrawing, regressing toward more childlike behaviour, clinging to caregivers, and freezing (not being able to move). As intellectually disabled people often depend on or feel they are dependent on others for their survival, their feelings of constant vulnerability can lead to frequent expressions of anxiety.

Treatment for verbal clients can include cognitive behavioural therapy. Anti-anxiety medications can help both verbal and non-verbal clients feel a much-needed sense of peace. However, repeatedly probing to find out what clients fear may not uncover a threat that others would recognize or believe is harmful. Therefore, finding ways to offer comfort to clients rather than simply seeking to understand a cause for their anxiety disorder is helpful.

Two disorders commonly suffered by people with intellectual disabilities are post-traumatic stress disorder and obsessive-compulsive disorder.

Post-traumatic stress disorder (PTSD) is a disorder in which an overwhelming traumatic event is re-experienced, causing intense fear, helplessness, horror, and avoidance of stimuli associated with the trauma. Nightmares, insomnia, flashbacks, mistrust, intense psychological distress, and self-medication with substance abuse are common in people with PTSD (Mayo Clinic, n.d.).

People with intellectual disabilities experience PTSD somewhat differently as they may not be able to describe the event that caused the trauma. Caregivers may not be aware of nightmares that are occurring. The flashbacks and memories may be vague and distorted and the memories confused. The flashbacks may seem so real that clients feel they are being traumatized again and again (Byrne, Hurley, & James, 2007). Conversely, flashbacks may be reported as additional traumatic events, with the result that records become inaccurate and make treatment difficult.

In one study, 75% of participants with mild to moderate intellectual disabilities had experienced at least one traumatic event during their lifespan, putting them at significant risk for PTSD (Martorell et al., 2009). Examples of traumas that intellectually disabled people face include physical and sexual abuse, loss of a parent, removal of children, involvement in vehicle or other collisions, and natural catastrophes. Reliving the trauma can result in acting-out behaviour (aggression or fighting back, inappropriate displays of sexuality, withdrawing in fear) that cannot be redirected.

Indicators Associated with Disorders of Mood: Anxiety

Post-traumatic Stress Disorder (PTSD)

Key Points for Caregivers

1. Monitor sleeping and **identify whether nightmares are occurring**. When possible, identify what the nightmares are about.
2. **Record situations when clients seem fearful**, particularly when there does not seem to be anything or anyone around who could hurt them. Notice if clients avoid certain situations or individuals by verbal and non-verbal resistance and behaviours.
3. Provide records of known traumatic events to caregivers and family members. Exchange information about these events to **determine whether they are new traumas or flashbacks**.

Obsessive-compulsive disorder (OCD), once thought to be simply a response to anxiety, is now considered a biological condition. Obsessions (the thinking component) are uncontrollable, persistent, and repeated thoughts or impulses. They frequently revolve around themes of contamination, aggression, orderliness, sex, and religion.

Compulsions (the behaving component) are the actions people take to try and relieve the pressure of the unrelenting obsessions. Compulsions are ritualistic patterns of behaviour often involving excessive cleaning, washing, counting, repeating, ordering, and arranging, or hoarding and checking. Repeated eye blinking, hair pulling, head banging, unusual behaviours when urinating or defecating, and self-mutilation are common.

People with OCD do not want to have obsessive thoughts, as those thoughts cause overpowering feelings of pressure and anxiety. They do not want to act on the thoughts either. However, because of the biological nature of the disorder, people are driven to believe that the only way to relieve the pressure of the obsessions is to keep acting on the compulsions. When people are in the process of acting on their compulsions, they can become very angry when their actions are interrupted. In essence, interruptions make the pressure and anxiety feel much worse.

People with intellectual disabilities often respond to interruptions of their ritualistic behaviour with aggressive retaliation such as hitting, spitting, and biting. They may not know why they must act this way, but they feel better when they do and desperately distressed when they do not.

In spite of a preoccupation with cleaning-centred behaviours, clients with this disorder may not achieve personal cleanliness and will present with extreme self-care deficits. Experts suggest that interrupting the behaviour simply increases the anxiety. With this in mind, caregivers can help by avoiding interrupting. For example, rather than interrupting a ritual such as repeated hand washing, a caregiver can ensure that hand lotion is available. With this disorder, the goal is not to prevent ritualistic behaviour, but to delay it.

The tricyclic antidepressant clomipramine (Anafranil) can have an anti-obsession effect. Side effects of the drug include a potential for seizures and withdrawal reactions.

Indicators Associated with Disorders of Mood: Anxiety

Obsessive-compulsive Disorder (OCD)

Key Points for Caregivers

1. **Delay rather than interrupt ritualistic behaviours.** Expect that clients may respond with aggression when redirected away from their repetitive behaviours. When caregivers view the behaviours through the eyes of clients, caregivers can acknowledge a client's belief that these behaviours are the only possible relief from unbearable anxiety.
2. **Prepare for and seek medical help immediately if seizures occur**, particularly if clients have, or have the potential for, seizure disorders and are taking the antidepressant medication clomipramine (also called Anafranil).
3. **Make comfort measures available when ritualistic behaviours result in physical symptoms.** For example, keep available hand lotion for excessive hand washing, and padding or helmets for

head banging.

Indicators Associated with Disorders of Behaviour

Personality Disorders

In the preceding sections, we have discussed psychiatric disorders that include or could include elements of psychosis (not being in touch with reality). Clients diagnosed with a thought disorder such as schizophrenia can be expected to have psychotic symptoms before they are treated with antipsychotic medications. We now turn our attention to disorders of behaviour, in which psychotic breaks from reality are not expected.

A personality disorder occurs when personality traits—behaviour patterns that reflect how a person perceives and relates to others and self—become rigid, maladaptive, and fixed. The disorder primarily affects the way an individual gets along with others. In the general population, people with personality disorders have a great deal of difficulty getting along with others and functioning well. Their behaviour can be disturbing to those around them. Often a pattern of repeating the behaviour occurs in different situations, despite efforts to make changes. Personality disorders are believed to be present from a young age, and while medications may be helpful, there are no antipersonality disorder drugs available as there are antipsychotic and antidepressive drugs.

In the intellectually disabled population, clinicians continue to question whether the same diagnostic criteria for personality disorders should be used (Alexander & Cooray, 2003; Chester, 2010). In part, this is because people with intellectual disabilities (especially those who are moderately and severely disabled) can have difficulty getting along with others for a variety of reasons, many of which can be explained in context. Often, caregivers and family members can support clients toward changing their behaviours, but this is not always possible for people diagnosed with a personality disorder. Without diagnostic criteria that have been adapted to the unique needs of the intellectually disabled, clinicians are often reluctant to impose on clients the stigma that can come with this diagnosis.

Borderline Personality Disorder

Borderline personality disorder is characterized by displays of hostility, emotional dysfunction, mood swings, and aggression (Wilson, 2001). Clients who have this disorder can overreact to typical requests and events. They can be verbally aggressive in ways that are very disturbing to victims. This verbal aggression can quickly lead to physical aggression. They frequently engage in self-injuring and suicidal behaviour.

Clients with borderline personality disorder do not seem able to see the connection between their behaviour and consequences. They may have encounters with the justice system. They tend to view people, circumstances, and events in their lives as either all good or all bad—a tendency that is referred to as *splitting*. This tendency can be destructive in that clients often polarize the people working with them into groups of either “good” or “bad.” Clients may become overattached to some people and make serious accusations against others. It is critical for caregivers to avoid siding with clients against other people or caregivers. Let clients know their accusations will be recorded, discussed, and acted on professionally during team meetings. It is important to ensure that communication with these clients does not suggest an alignment of the caregiver and client against any other member of the team.

Indicators Associated with Disorders of Behaviour: Borderline Personality Disorder

Key Points for Caregivers

1. Gather as much information as possible about clients' **patterns** of overreacting and behaviour that is harmful to self or others. Identify if the patterns began occurring at a young age and whether any elements of the behaviour have changed and improved over time and with support.
2. With borderline personality disorder, **consistent communication among caregivers** is critically important. Divisions among caregivers can occur if clients split or view individuals around them only as all good or all bad.

Conclusion

In this chapter we have discussed the psychiatric disorders of thinking, mood, and behaviour. These disorders cause so much distress that clients cannot function and enjoy their lives. We have described key indicators of these disorders and emphasized relevant observations that caregivers must watch for and attend to.

Disorders of thinking include schizophrenia, dementia, and psychosis. Disorders of mood include depression (for example, major depression or bipolar affective disorder) and anxiety (for example, post-traumatic stress disorder and obsessive-compulsive disorder). Disorders of behaviour include borderline personality disorder. None of the indicators that are present with these disorders are displayed on purpose. Just as the nature of physical illnesses causes people's minds and bodies to act in certain ways, mental illness does as well. Understanding the links between difficult behaviours and diagnosed psychiatric disorders can make all the difference in supporting dually diagnosed clients toward success.

Chapter Audio for Print

This chapter contains a number of short audio clips. If you are reading this in print, you can access the audio clips in this chapter by scanning this QR code with your mobile device. Alternatively, you can visit the book website at opentextbc.ca/caregivers and listen to all the audio clips.

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CHAPTER 4: COMMON PHYSICAL CONCERNS

Factors impacting health

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Introduction

The life expectancy of people with intellectual disabilities is increasing. This is particularly noticeable for persons with Down syndrome, for whom the average life expectancy has risen from 26 years in 1983 to 55 years today, and many now live into their 60s and 70s (Emerson & Baines, 2010; National Association for Down Syndrome, 2012; Ouellette-Kuntz et al., 2004). Severity of disability affects longevity, however, and life expectancy tends to decrease as the severity of intellectual disability increases. Largely this occurs because people with severe intellectual disabilities experience a greater prevalence of associated health conditions such as severe mobility impairments, seizure disorders, vision and hearing impairments, swallowing difficulties, and inability to independently feed oneself (Ouellette-Kuntz et al., 2004). Epilepsy, for example, affects 22% to 33% of all people with intellectual disabilities, but increases as the severity of disability increases; half of all people with severe intellectual disabilities have epilepsy (Royal College of Nursing, 2006). This compares to a prevalence rate of about 0.5% for the general population.

Individuals with mild intellectual disabilities have an average life expectancy that is near that of the general population. When death does occur, it is commonly due to the same age-related health conditions that take the lives of members of the general population: cardiovascular disease, cancer, stroke, respiratory conditions, and diabetes-related complications (Horwitz et al., 2000). Still, while the overall life expectancy of people with intellectual disabilities is increasing, it remains about 10 years less than that of the general population. On average, people with intellectual disabilities have twice as many health conditions as others, and are from three to six times more likely to die from preventable causes (Department of Health, 2009; Havercamp, Scandlin & Roth, 2004). In fact, in a review commissioned by Britain's Department of Health, 90 of 244, or 37%, of the deaths that were reviewed were found to be avoidable (Heslop et al., 2014).

In this chapter, we discuss the overall health status of people with intellectual disabilities and mental illness as well as factors that have an impact on health status and lifespan. We describe health and wellness challenges of particular importance to dually diagnosed people and identify strategies for assisting people who are experiencing specific challenges. The importance of including people with intellectual disabilities in health promotion programs and activities is also discussed.

Health Status

There is broad agreement that people with intellectual disabilities, on the whole, have poorer health, greater health needs, and shorter lives than the general population. However, evidence shows time and time again that the considerable health needs of people with intellectual disabilities are often under- or undiagnosed, or poorly managed (Balogh et al., 2008; Department of Health, 2001; Emerson, 2011; Emerson & Baines, 2010; Morin et al., 2012). For example, the proportion of extracted teeth to filled teeth for people with intellectual disabilities has been reported to be higher than in the general population, indicating that intellectual disability is a risk factor that increases the likelihood of extraction. When Special Olympics Inc. screened 3,500 of its athletes at the Dublin World Summer Games, they found that:

- 30% failed hearing tests (this is six times greater than the rate in the general population)
- 35% had obvious signs of tooth decay, while 53% showed clear evidence of gum disease
- 12% reported tooth or mouth pain at the time of examination (in contrast with about 2% of the general population reporting pain at the time of dentist visits)
- 33% required corrective lenses, but only half of them had glasses at the time of examination
- 50% of the athletes had one or more foot diseases or conditions
- All of them (who had an average age of 24.7 years) had high rates of low bone mineral density (increasing the risk for fractures), comparable to rates reported in women aged 65 and older (Corbin, Malina, & Shepherd, 2005)

Health Status

Key Points for Caregivers

Those who support and care for persons with intellectual disability can get clear signals from findings of research with Special Olympic athletes.

1. Arrange routine vision and hearing examinations, particularly for age-related deterioration. Adults with Down syndrome are particularly likely to have vision and hearing problems. Those over the age of 30 are at increased risk for early development of cataracts, refractive errors such as near- and farsightedness, and degeneration of the cornea.
2. Encourage healthy dietary habits and promote or provide regular daily dental hygiene. Schedule routine dental appointments for cleaning, examinations, and maintenance of oral health. Individuals with intellectual disability are much more likely than individuals without disability to report that

they have not had their teeth cleaned by a dental hygienist within five years, or that they have never had their teeth cleaned by a dental hygienist.

3. Promote or provide proper foot care, ensuring that cleanliness is maintained, nails are correctly cut, and clean socks and proper-fitting shoes are worn. It's been said that to determine how well a person with disability or dependency needs is being cared for, check the condition of his or her teeth and toenails. Although this form of assessment is far too simplistic, it does provide a telling measure.

4. Provide well-balanced meals and regular weight-bearing exercise such as walking to promote overall health and bone maintenance. Individuals with Down syndrome as well as underweight or small-boned individuals are more at risk of bone loss and osteoporosis. Also at risk are individuals who experience delayed puberty or early menopause, which can accompany some conditions linked with intellectual disability.

When surveyed about the condition of their own health, individuals with intellectual disabilities are much more likely than individuals without intellectual disability to report poor or only fair health, and much less likely to describe their health as excellent. They indicate that they are more likely than others in the general population to live an inactive lifestyle and less likely to be physically fit (Campbell, 2001). As a result, people with intellectual disabilities are also more likely than others to be overweight (or in some cases underweight) and are at increased risk for illnesses and diseases associated with weight-related conditions. High rates of victimization also place both children and adults with intellectual disabilities in positions of health and mental health risk. Children with intellectual disabilities, for instance, are four times more likely to be abused than children without intellectual disabilities, while women with intellectual disabilities are 50% more likely to be sexually abused than women without intellectual disability (Horwitz et al., 2000; Sobsey & Doe, 1991).

In all cases, potential health complications associated with specific conditions deserve careful vigilance. For example, individuals with Down syndrome are more likely than other people to have congenital heart defects, thyroid disease, leukemia, and Alzheimer-like neurodegeneration. They are also at greater risk for weight and lifestyle-related problems such as cardiovascular disease and diabetes. Because of the high prevalence of associated conditions, Sullivan and colleagues (2006) have argued that patients with intellectual disabilities require more attention from health care providers than most other patients.

Factors Affecting Health Status

People with intellectual disabilities have associated health conditions that account for some premature mortality. But a related problem is that they also have less access to adequate health services. This means that the presence of intellectual disability decreases the likelihood that an individual will receive accessible information and opportunities important to leading a healthy lifestyle. It also means that when the individual is ill, he or she is less likely than members of the general population to receive treatment, and more likely to receive inadequate or inappropriate treatment, if treatment is provided at all. A report by Britain's leading advocacy group for people with intellectual disabilities, *Death by Indifference* (Mencap, 2007), asserts that disparities in health status and health service are due to institutional discrimination. From the organization's perspective, institutional discrimination occurs when people with intellectual disabilities are not valued in a manner equal to that of other citizens needing health services. This factor, along with failure to understand the needs of people with intellectual disabilities and to adapt service delivery to them means that their health needs are sometimes not met.

Landmark documents from Britain (*Valuing People* and *Valuing People Now,* Department of Health, 2001, 2009) and the United States (*Closing the Gap,* U.S. Department of Health and Human Services, 2002), among others, agree that health services for people with intellectual disabilities have been inadequate, and they call on health care professionals to confront their own prejudices and address their own educational needs, where they exist, so that they are better prepared to provide services equal to those given to the general population. As well, a sizable body of literature supports the idea that people with intellectual disabilities have been and remain inadequately served by the health care system. In most cases, disparity in access to adequate health services does not represent a conscious decision but a long-established or entrenched way of practising. The following factors, separately and in combination, contribute to the comparatively poor health and generally shorter lifespans experienced by people with intellectual disabilities.

Lack of health care providers who are willing to provide or interested in providing care and treatment for individuals with intellectual disabilities. Most people with intellectual disabilities have always lived in their home communities, and de-institutionalization has repatriated the great majority of others who were previously institutionalized. However, some mainstream health care practitioners still don't see people with intellectual disabilities as being their responsibility. Instead, people with intellectual disabilities are viewed as being the responsibility of a specialized system that deals specifically with this population. The result is that some people with intellectual disabilities are not able to have their health needs met (Mencap, 2004).

Absence of adequate preparation for health care providers. The World Health Survey of 51 countries (World Health Organization/World Bank Group, 2011) reported that people with disabilities were more than twice as likely as people without disabilities to describe health care provider skills that were inadequate to meet their needs. This survey also found that people with disabilities were three times as likely to be denied needed health care.

Surveys have found that few health care practitioners are educated about intellectual disabilities, and many admit that they have insufficient education to effectively meet the health needs of patients with intellectual disabilities (Mencap, 2004; NHS Scotland, 2004; Ouellette-Kuntz et al., 2004; Reichard & Turnbull III, 2004; U.S. Department of Health and Human Services, 2002). In one survey of 215 general practitioners, for example, 75% indicated that they had no training related to treating people with intellectual disabilities (Mencap, 2004). The resulting lack of confidence and feelings of inadequacy have contributed to practitioners' reluctance to treat and care for patients with intellectual disabilities, which is commonly reflected in the following ways:

- Uncertainty about how to interact with patients with intellectual disabilities
- No understanding of illness presentation by individuals with intellectual disabilities, particularly in the case of patients with severe disabilities and limited verbal skills (often experienced as inability to correctly interpret behavioural clues as indicators of illness-related or anxiety-related distress)
- Inadequate understanding of health problems and issues experienced by individuals with complex developmental disabilities and intellectual disability
- Inadequate understanding of methods to adapt to challenges in promoting mutual comfort and effective communication during examination and treatment processes
- Misconceptions about intellectual disabilities

- Uncomplimentary attitudes about people with intellectual disabilities

On the other hand, education has been shown to better prepare health care providers to treat and care for patients with intellectual disabilities. Education is effective in changing misconceptions, challenging and overturning uncomplimentary attitudes, and producing greater willingness to treat and care for patients with intellectual disabilities (U.S. Department of Health and Human Services, 2002).

The nature of the health care system. Modest fee-for-service rates, along with significant capital expenditures, operational costs, and high patient volume, interfere with the ability of many primary health care providers to contribute the time needed to effectively assess and treat patients with intellectual disabilities. Depending on individual characteristics, patients with intellectual disabilities may require longer appointments or a series of shorter appointments. In some cases, extra orientation and follow-up time may be needed to promote patient comfort, familiarity with procedures, and general understanding (Reichard & Turnbull III, 2004; Royal College of Nursing, 2006). Unwillingness or inability to accommodate the longer appointments required by many patients with intellectual disabilities has an impact on the adequacy of health care provision and may discourage contact with health care providers entirely.

The general unfamiliarity of health care professionals with people with intellectual disabilities can also be problematic. Confusion about laws on consent and the rights of individual patients with intellectual disabilities, along with absent or inaccurate information about intellectual disabilities, can cause health care providers to make decisions based on faulty assumptions.

The nature of the intellectual disability service and support system. In its *World Report on Disability*, the World Health Organization/World Bank Group (2011) reported that many residential and home care workers are poorly trained and poorly paid. This is commonly the case for those who support people with intellectual disabilities as it is for those who work in the broader home care service industry. This means that, in many cases, salaried support providers have limited skills in recognizing and acting on health care problems (Australian Association of Developmental Disability Medicine Inc. and National and NSW Councils for Intellectual Disability, n.d.). In places where formalized education does exist, as across much of Canada, the sheer size of the demand for support providers, along with comparatively poor salaries, means that individuals without formal credentials regularly give direct support. For these individuals, support provision is often a brief stop before moving on to something else.

Because high support-staff turnover rates are common within most intellectual disability-related service systems (exceeding 100% per year in some cases), knowledge about and understanding of supported individuals is often compromised (Melrose et al., 2013; Royal College of Nursing, 2006). This means that individuals with intellectual disabilities may not have advocates or surrogates who are sufficiently familiar with their personalities, communication styles, idiosyncrasies, and physical health issues. This also has negative implications for the psychosocial health of individuals with intellectual disabilities, who have no control over the continuance of significant relationships in their lives.

The service and support system is shifting in emphasis from a medical model to a social or human rights model that gives attention to inclusion and participation, autonomy, and individual choice. This, however, may make it more difficult for some support providers to notice and respond to health matters (Royal College of Nursing, 2006). Support providers may also hold prejudices against the health care system, based on their familiarity with the troubled historical relationship between the health care system and people with intellectual disabilities. In one case, support providers in a community residence in the United States refused to give prescribed antidepressant medications to a person with intellectual disabilities, citing well-known concerns about the overuse of antipsychotic medications with the intellectual disability population. In this case, the distrust of the support providers, at least in part, may have unwittingly contributed to the person's suicide some time later (Brown, 1990).

Poor socioeconomic conditions. Intellectual disability occurs across all socioeconomic sectors in all societies. Although intellectual disability "seems to know no boundaries, it is observed in disproportionately high numbers in the more vulnerable segments of the population such as the poor, the disenfranchised, and ethnic minorities" (Beirne-Smith, Ittenbach, & Patton, 2002, p. 208). This imbalance, however, appears to be the case only for people with intellectual disabilities who have IQs higher than 50; comparatively severe intellectual disabilities is evenly distributed among socioeconomic divisions (Department of Health, 2001).

While the reasons for the uneven distribution of mild intellectual disabilities are not entirely clear, individuals with an income below the poverty line are three times more likely to have intellectual disabilities than those who don't experience poverty. Though people with intellectual disabilities (and people with disabilities, generally) are overrepresented in low-income and unemployed sectors, poverty in itself creates a web of conditions that dramatically increases the risk for developmental concerns and ill health (Drew & Hardman, 2004). For example, poverty means that food and adequate housing are less affordable, if affordable at all. Poor children are more likely to experience malnutrition and exposure to various environmental contaminants and toxic substances.

In general, disadvantaged social groups are more likely to be poor and at greater risk for illness and disability. In Canada, for instance, the poverty rate for young children who are Aboriginal, new immigrants, or members of a visible minority is about twice that of all children (Campaign 2000/2003). In the United States, the rate of poverty for people who identify as African-American is about three times that of people who are listed as non-Hispanic White (8% vs. 24.1%; U.S. Bureau of the Census, 2003).

While being poor or coming from a minority population increases exposure to conditions that are known to produce illness and disability, these circumstances also place individuals at the core of a complex interaction of factors that increase the risk of illness and disability. Vulnerable people have the additional risk of less access to essential health and social services as others (Beirne-Smith, Ittenbach, & Patton, 2002). It is a paradox that these essential health and social services seem to be least available to the people who most need them.

Dependency and limited communication skills. The dependence of people with intellectual disabilities on others can interfere with their ability to resolve health-related issues and problems. In many cases, primary support providers must be able to detect and report symptoms of illness that individuals with intellectual disabilities may not be able to communicate themselves (Horwitz et al., 2000; Nocon, 2006; Ouellette-Kuntz et al., 2004; Reichard & Turnbull III, 2004). Limited communication skills reduce the chances of identifying and reporting illness early (if reporting occurs at all), and often inhibit or prevent the first-hand descriptions of illness that health care providers commonly rely on for accurate diagnosis and treatment.

Individuals experiencing illness are inclined to automatically defer to others in perceived authority and the wish to please others, which can also interfere with accurate diagnosis and treatment of health problems. This inclination is characterized by the tendency to give the response that the ill person believes the health care provider is seeking, or the response that the ill person thinks is most likely to gain approval. In this context, health care and support providers need to be conscious of asking questions in an understandable manner and avoid leading questions that suggest a preferred answer. When the accuracy of an ill person's response is in doubt, it can be helpful to pose the original question again in another form. If the question requires a *yes* or *no* response, asking the same question in its opposite form can help confirm the accuracy of the original reply (Royal College of Nursing, 2006).

Like many people, individuals with intellectual disabilities may be reluctant to seek medical care because the diagnostic process, imagined consequences, and anticipated procedures frighten them. This feeling can be compounded by concern about new and unfamiliar surroundings, and by apprehension about interacting with unfamiliar health care providers.

Factors Affecting Health Status

Key Points for Caregivers

People with intellectual disabilities have the right to be as healthy as anyone else. They also have the right to the same health care access and treatment as others within the general population. Examples of legislation that protect the equality rights of all persons with disability are section 15 of the Canadian Charter of Rights and Freedoms, the U.S. Americans with Disabilities Act, and Britain's Disability Discrimination Act. In addition, the United Nations Convention on the Rights of Persons with Disabilities is a declaration of commitment to equality rights that has been ratified by 143 countries.

To promote health care access and adequate treatment, those who support and care for people with intellectual disabilities are encouraged to take responsibility for each of the following activities:

- ***Maintain ongoing records regarding health status***, including changes in weight, eating and elimination patterns, sleeping patterns, mood, behaviour, illnesses, medications (including effects and side effects), communication methods, issues related to specific conditions and situations, and any concerns that develop, along with events that occurred prior to the development of those concerns.
- ***Act as a resource for health care professionals;*** for example, ongoing health status records can be shared during appointments. Formal assessment tools such as the Comprehensive Health Assessment Program (CHAP) can be used by the health professional and support provider to develop a complete health history (Lennox et al., 2007). The CHAP is available as a 21-page booklet with two parts. The first part is completed by the support provider in advance of the appointment and provides a health history along with a description of the issue that prompted the appointment with the health professional. The second part is completed by a general practitioner and involves a review of the health history and then a targeted examination of the individual. At the end, a health action plan is developed. A feature of the CHAP is that it prompts the doctor to be aware of health conditions that are commonly missed or poorly managed, as well as health conditions that occur to individuals with specific syndromes. The CHAP booklet can be downloaded from certain CHAP-related websites on request by representatives of support agencies.
- ***Arrange appointments with health care providers*** that are long enough to accommodate the person's needs. This may include arranging health care appointments during clinic times that are comparatively

quiet. In some cases, a preliminary visit or visits may need to be scheduled for the support provider to discuss the impending health-related appointment with a cooperating health care provider. Information important to a successful appointment can be discussed, such as the client’s method of communication (verbal or by signing, computer assistance, pictures, symbols, or other means). Other impactful issues can be discussed, such as the need to provide health-related information in small amounts and to allow sufficient time for information processing and understanding. In addition, the support provider should obtain a practical understanding of expectations and procedures that the client will encounter so that the support provider can adequately prepare the individual for the appointment.

- ***Explain and/or demonstrate behaviours that will be expected or procedures that will be performed*** when at the health care provider’s, to promote understanding and reduce anxiety. This should be done in advance of an appointment. For some individuals, this may require a desensitization process over a period of days, weeks, or months. In this case, a task analysis should be developed that breaks down an expectation or procedure into its component parts, so that each part can be taught in succession until the complete expectation or procedure is understood and tolerated (see Table 4.1).

Table 4.1 Example of task analysis

ACTIVITY: **GETTING A FLU SHOT** Name of Trainer:

	STEPS	STEP COMPLETED	DATE COMPLETED	COMMENTS	TRAINER INITIALS
1	The nurse will ask you to roll up your sleeve.	YES NO			
2	The nurse will clean a small part of your skin near the top of your arm.	YES NO			
3	A needle will be put in your arm and then removed. It may hurt a bit.	YES NO			
4	A small band-aid will be put over the spot on your arm where the needle was given.	YES NO			
5	You can now roll down your sleeve.	YES NO			

Notes:

1. Pictures can be used at each step of the procedure along with verbal instructions.
2. For individuals with severe disability, the instructor will need to demonstrate each step with the individual while using a model for the actual needle.
3. A reinforcer may need to be given for individuals with severe disability and anxiety.

Common Health Challenges

Constipation

By definition, constipation occurs when a person has two or fewer bowel movements in a week. This is commonly accompanied by straining during bowel movements or by simply having difficulty with bowel movements (for example, trying for 10 minutes without success). The inability to completely evacuate the bowels and producing hard or pencil-thin stools are also characteristic of constipation. Support providers should view a swollen abdomen, abdominal pain, and vomiting as possible indicators of constipation.

Though at one point or another constipation affects nearly everyone, chronic constipation occurs more commonly in people with intellectual disabilities. Morad and colleagues (2007) found that 8% of more than 2,000 individuals in Israeli residential facilities were experiencing constipation at the time of their survey, although only about 2% of the general population is thought to have constipation at any given time.

Constipation is more likely to affect those with severe or profound disabilities, those with mobility restrictions, or those who are otherwise inactive. In one study, almost 70% of institutionalized persons with severe or profound intellectual disabilities were experiencing constipation at the time of the study (Bohmer et al., 2001). Neurological conditions such as cerebral palsy place individuals at greater risk for constipation. It is also more likely to affect those with inadequate hydration and limited food choices (inadequate dietary fibre and excessive amounts of dairy products), and those taking long-term medications that produce constipation as an incidental consequence. Examples of these medications are anticonvulsants, benzodiazepines (minor tranquilizers), and antacids containing calcium. In some cases, overreliance on laxatives contributes to constipation becoming chronic. When symptoms are unrecognized in people with intellectual disabilities, constipation can pose a serious threat to health, including the possibility of death (Royal College of Nursing, 2006).

Common Health Challenges: Constipation

Key Points for Caregivers

1. Prepare or promote the preparation of well-balanced meals that include adequate sources of fibre such as fruits, vegetables, and whole grain breads.
2. Encourage adequate fluid intake. Eight glasses of water or other fluids each day can be considered adequate, unless an individual has fluid intake restrictions or other requirements. Caffeine-containing drinks have a dehydrating effect and milk or dairy-based drinks may be constipating for some people.
3. Promote or provide regular daily exercise. For individuals in wheelchairs, occasional side-to-side movement, if possible, or exercise while seated in the chair may be helpful. A physiotherapist may be able to recommend exercises and activities.
4. Encourage supported individuals to move their bowels when they feel the urge.

Seek medical assistance if:

1. Constipation is experienced for the first time or there has been a change in bowel routine
2. Constipation does not respond to natural remedies such as increased dietary fibre or fluid intake, or to replacing sedentary activity with regular exercise such as walking or swimming
3. Blood is evident in stool or during bowel movements, or rectally at any other time
4. Unplanned weight loss occurs
5. Pain occurs with bowel movements, or abdominal pain or cramps occur
6. Nausea or vomiting occur
7. Constipation lasts for more than two weeks

Epilepsy

Epilepsy is a common condition in people with intellectual disabilities, with prevalence increasing with the severity of the disabilities. In situations where intellectual disabilities and cerebral palsy coexist, and for individuals with severe intellectual disability, the prevalence of epilepsy is about 50%. The cause is often complex, and in 50% to 60% of cases the cause is unknown. The same cause may produce both intellectual disability and epilepsy or, in some cases, epilepsy itself may be responsible for the intellectual disability. In any case, epilepsy contributes to the morbidity and mortality profiles of many people with intellectual disabilities and represents a condition requiring careful observation (Royal College of Nursing, 2006; Santos-Teachout et al., 2007).

By definition, epilepsy is characterized by sudden, brief changes in the brain's electrical activity. It is a symptom of a neurological disorder and is expressed in the form of seizures (Epilepsy Canada, n.d.). Seizures can be generalized or partial, depending on the extent of brain involvement. If there is extensive activity affecting the entire brain, then seizures are generalized. If the activity is localized in a specific area of the brain, the seizure is considered partial. A single seizure does not constitute epilepsy, nor do seizures associated with conditions that may cause event-specific seizure activity, such as illness with an accompanying fever in young children (febrile seizures). An actual diagnosis of epilepsy depends on an observable pattern of seizure activity along with confirming results from specific diagnostic testing.

Events that may trigger seizures (Epilepsy Canada, n.d.) include:

- Stress
- Poor nutrition
- Missed medication
- Flickering lights
- Skipping meals
- Illness, fever, and allergies
- Lack of sleep

- Emotions such as anger, worry, and fear
- Heat or humidity

Whether generalized or partial, epileptic seizures can take a number of different forms. The most common form or type of epileptic seizure is the *complex partial seizure*, which accounts for 40% of all seizures. These seizures are often preceded by an aura, which is a strange sensation such as an odd smell, strange taste, tingling sensation, unusual sound, or a sense of uneasiness or dread. An aura is actually a *simple partial seizure*, and may be the only form of an individual's seizure activity; this is the case in 20% of seizures. In the case of complex partial seizures, however, an aura may signal that a seizure is about to take place. An individual who then experiences a complex partial seizure may appear dazed and confused and may engage in random walking, mumbling, head turning, and pulling at his or her clothes. There is a change in the individual's level of consciousness (the individual is not fully conscious, nor is he or she unconscious), with the seizure itself lasting from 30 seconds to three minutes.

Tonic–clonic seizures (previously called *grand mal seizures*) are generalized, and are the kind of seizure that commonly comes to mind when epilepsy is mentioned, though they only account for 20% of all seizures. The characteristic pattern of tonic–clonic seizures may or may not include an aura. When an aura is present, it provides a warning that may permit the individual time to lie down on the floor or may allow someone nearby to assist the individual to the floor before he or she becomes unconscious and otherwise falls. The aura may be accompanied by a cry that also serves a warning that a seizure is about to take place.

Normally, a tonic–clonic seizure lasts from one to a few minutes and has two distinct phases. The tonic phase is characterized by stiffening of the body and is followed by the clonic phase, characterized by energy release in the form of rhythmic jerking of the extremities, otherwise called a *convulsion*. In the tonic phase, breathing may appear to be suspended (lips may turn blue). During the seizure, the individual may drool and may lose bladder and/or bowel control. After the clonic phase and then recovery, breathing may appear to be stertorous or audible, much like snoring. While the individual may bite his or her tongue, at no time should a support provider try to insert anything into the individual's mouth. During the tonic phase the jaw is tightly clenched, and during the clonic phase teeth commonly chatter. Attempting to insert an object such as a spoon into the individual's mouth to compress the tongue at any point during a seizure may cause injury. Contrary to the once popular myth, people cannot swallow their tongue. Once a seizure has run its course, the individual is typically confused, tired, and may have a headache. He or she will have no memory of the seizure and will require time to rest.

When assisting individuals experiencing tonic–clonic seizures:

- Stay calm.
- If possible, assist the person to the ground.
- Protect the person from injury by removing nearby obstacles that he or she may bang up against.
- Do not restrain the person.
- Do not insert anything into the person's mouth.
- Time the duration of the seizure.
- Call for medical assistance if the seizure lasts for five minutes or more.
- Once the seizure is over, place the person in the recovery position (on his or her left side) and allow him or

her to rest, checking back periodically.

- Reassure and reorient the person when he or she has recovered.

Absence seizures (previously called *petit mal seizures*) are very brief, lasting for a matter of seconds. They occur more often to children than to adults, and when they occur, the individual gives the impression of daydreaming, momentary inattention, or staring. Because of their brief nature, others who may be with individuals experiencing these seizures may not notice the seizure activity.

Other types of epileptic seizures are *myoclonic*, involving a single or repetitive jerking of muscles without a loss of consciousness, and *atonic*, also called akinetic or drop seizures. In atonic seizures, loss of muscle tonicity occurs and the individual is unable to sit or stand; if standing, the individual will fall to the ground without a loss of consciousness. Like tonic–clonic seizures, atonic seizures create a risk for injury.

Seizures that last for more than five minutes tend not to resolve without medical intervention. Therefore, seizures that last for five minutes or longer, or two or more seizures that occur in succession without intervening periods of recovery or return to normal functioning, should be considered a medical emergency. This condition is known as *status epilepticus* (Brophy et al., 2012). Status epilepticus can occur in cases of non-convulsive as well as convulsive epilepsy. In all such cases, an ambulance should be called.

Common Health Challenges: Epilepsy

Key Points for Caregivers

1. Be conscious of situations and conditions that are likely to trigger seizures for supported individuals. Avoid or reduce exposure to triggers whenever possible.
2. Provide appropriate assistance to the individual if a seizure does occur.
3. After a seizure, record the conditions under which the seizure occurred, along with a description of the seizure activity. Describe how long the seizure lasted and emergency measures if needed. Describe any events that accompanied the seizure, such as loss of bladder control or injury. Describe the nature of the recovery after the seizure.

Respiratory Disease

Though the vast majority of individuals with intellectual disabilities live in community settings, existing institutions characteristically house a disproportionate number of individuals with severe and profound intellectual disabilities. Difficulties with movement, independent mobility, and swallowing are especially high within this population. As a result, and because of the risks inherent in community living, institutionalized individuals (and individuals in other community situations) are particularly susceptible to respiratory infections through transmission of infectious agents, aspiration (breathing food or liquid into the lungs), and reflux (see discussion on gastrointestinal problems). Almost half the deaths that occur in institutions are attributed to the respiratory illnesses pneumonia and influenza.

Individuals with Down syndrome are also at particular risk for respiratory infections. These individuals tend to breathe through the mouth and have physical malformations that can interfere with sinus drainage, and a poor immune system that makes them susceptible to infections (Horwitz et al., 2000; Royal College of Nursing, 2006).

Cancer

The rate of gastrointestinal cancer in individuals with intellectual disabilities is about twice the rate as that observed in the general population. This may be due to gastrointestinal reflux (see discussion on gastrointestinal problems) and chronic constipation that are comparatively common in individuals with severe and complex disabilities living in community settings. Individuals with Down syndrome are at risk for a particular form of cancer called lymphoblastic leukemia (Horwitz et al., 2000).

Cardiovascular Disease

Cardiovascular disease accounts for as much as 50% of deaths among people with intellectual disabilities, depending on the population reviewed. Because of lifestyle factors that more closely resemble those of the general population, individuals with mild intellectual disabilities (about 85% of people with intellectual disabilities) are more vulnerable than individuals with more severe disabilities.

Congenital heart defects affect 30% to 60% of children with Down syndrome, regardless of severity. Congenital heart defects are also common in children with Williams syndrome. With advances in medical technology, however, survival rates have improved dramatically over the years. Vigilance remains important for at-risk populations, with electrocardiogram and echocardiogram screenings recommended for infants with Williams or Down syndrome (Horwitz et al., 2000).

Diabetes

The likelihood of developing diabetes appears to be greater for people with intellectual disabilities than for the general population. This seems to be the case even more for people with Down syndrome, who appear to have a greater likelihood of developing the disease at an earlier age (Horwitz et al., 2000; Royal College of Nursing, 2006).

Gastrointestinal Problems

Comparatively high rates of *helicobacter pylori* (*H. pylori*) infection are found in people with intellectual disabilities who are in community living situations or who attend day centres or vocational workshops. *H. pylori* is a bacterium that usually infects the stomach and, along with reflux and chronic constipation, is viewed as a predisposing factor for the greater occurrence of gastric cancer observed in people with intellectual disabilities (Royal College of Nursing, 2006).

Gastroesophageal reflux disease and reflux esophagitis occur frequently in individuals with severe or profound intellectual disabilities. These are chronic conditions caused by stomach acid entering the esophagus. Their prevalence in people living in institutions is high. Individuals with Fragile X syndrome also have particular vulnerability, as do individuals with scoliosis, cerebral palsy, and those taking anticonvulsant medications or other benzodiazepines. Though easily treated, gastroesophageal reflux disease is often unnoticed in individuals with intellectual disabilities, which may be why they have a higher rate of esophageal and gastrointestinal cancer. Vomiting (along with blood in the vomit), effortless regurgitation of meals after eating, and depressive symptoms, should raise clinical suspicions (Santos-Teachout et al., 2007).

Sensory Impairments

The available data show that as many as 72% of all children with intellectual disability have ophthalmological problems (compared with 25% in the general population). Common vision impairments are refractive errors, strabismus (the muscles of the eyes not well coordinated and the eyes not lining up in the same direction), cataracts (clouding of the lens of the eye), keratoconus (thinning cornea and bulging outward in a cone shape, causing blurred vision), nystagmus (repetitive, uncontrolled movements of the eye that can result in poor vision), and poor visual acuity (Royal College of Nursing, 2006). Individuals with severe intellectual disabilities are more likely to have visual impairments than individuals with mild intellectual disabilities. They are also more likely to have hearing problems, with about 40% of individuals with severe disabilities believed to have hearing impairments (Santos-Teachout et al., 2007).

People with intellectual disabilities tend to experience vision and hearing deterioration earlier than the general people. In addition, some causes of intellectual disabilities, or their co-occurring conditions, also produce sensory impairments. Cerebral palsy, Fragile X syndrome, and fetal rubella syndrome are associated with such impairments. Adults with Down syndrome who are over the age of 30 are predisposed to develop premature age-related cataracts, refractive errors, and degenerative corneal problems. They are also at risk for early age-related hearing loss. On the whole, deafness is comparatively common in people with intellectual disabilities, but it is frequently unrecognized or poorly managed (Horwitz et al., 2000).

Obesity

Although obesity, generally, is on the rise in North America, obesity levels in people with intellectual disabilities remain higher than in the general population (Horwitz et al., 2000; Rimmer & Yamaki, 2006). Adults with mild intellectual disabilities, especially women, are most vulnerable. Individuals with comparatively severe intellectual disabilities are less likely to be overweight or obese, likely because of the greater menu control maintained by support providers. Therefore, risk of obesity decreases as the severity of disability increases (Stancliffe et al., 2011).

Living situations and the cause of the disability are also factors and have a noticeable impact on obesity prevalence. Individuals with intellectual disabilities who live at home or on their own, for instance, have a higher rate of obesity than those in community living situations. Individuals who live their own are more likely to have unbalanced meals and rely on convenience foods (Horwitz et al., 2000; Royal College of Nursing, 2006).

Some genetic conditions or chromosomal irregularities that cause intellectual disability are associated with weight-related problems. For example, Down syndrome or Prader-Willi syndrome are correlated with weight gain or obesity (a primary feature of Prader-Willi syndrome is compulsive overeating). Other factors that create risk for obesity and its inherent dangers are:

- ***The tendency to be physically inactive*** (In a survey of 1,500 people with intellectual disability in 14 European countries, more than 50% of individuals reported sedentary leisure time activities such as TV watching or reading [Walsh, Kerr, & van Schrojenstein Lantman-Devalk, 2003].)
- ***Dependence on others*** to create opportunities for physical activity
- ***Lack of access*** to or difficulty understanding health promotion materials and campaigns that encourage healthy lifestyles
- ***Greater likelihood (compared with the general population) of being on medications*** such as anticonvulsants or antipsychotics that have weight gain as a side effect (Horwitz et al., 2000; van Schrojenstein Lantman-De Valk, Metsemakers, Haveman, & Crebolder, 2000)

Some individuals with intellectual disabilities are at comparatively greater risk for being underweight. This is the case for individuals with metabolic disorders such as phenylketonuria (PKU), in which certain nutrients cannot be effectively broken down and used by the body, and for individuals with swallowing or feeding problems that can be attributed to severe neurological damage (Royal College of Nursing, 2006). An additional concern for individuals with swallowing or feeding problems is the potential for choking and for aspiration. In this case, the principal caution is that those who assist with feeding must understand proper techniques to lessen the risk for choking and aspiration.

Where weight-related or swallowing/feeding-related concerns exist, appropriate health care providers should be consulted. For instance, a nutritionist can develop a weight management program for individuals whose weight presents a health concern. Similarly, an occupational therapist can provide instruction about how to correctly assist individuals who have swallowing or feeding challenges, as may be the case with individuals who have severe forms of cerebral palsy. For example, the therapist will be able to demonstrate alternative techniques to the dangerous practice of “bird feeding” (feeding an individual with his or her neck extended and increasing the risk of aspiration of food or liquid into the lungs).

Medication Use

In its survey of 14 European countries, the Pomona Project found that 65% of people with intellectual disabilities used one or more medications (Walsh et al., 2003). About 50% used nervous-system-related medications, principally anti-epileptics, antipsychotics, and antidepressants. High rates of polypharmacy, or use of multiple medications, mean that individuals with intellectual disabilities are more susceptible to drug interactions than is the general population. Such interactions may produce, among other possibilities, sedation, confusion, constipation, balance difficulties and falls, incontinence, weight gain, impairments in epilepsy management, metabolic effects, and movement-related disorders (Ouellette-Kuntz et al., 2004). Therefore, support providers and health care providers must understand the effects and side effects of medications used by clients and patients with intellectual disabilities, and the extent to which those clients and patients experience them.

The use of antipsychotic medications with people with intellectual disabilities has been controversial and is often high in long-stay institutions. Emerson and Baines (2010) report use by almost 45% of institutionalized people in the United Kingdom. Use diminishes to 20% to 30% in community-based residences, and to around 10% in family homes. Individuals who are most likely to receive antipsychotic medications are those who reside in congregate living situations, are mobile, and are overweight. Antipsychotics cause weight gain, however, so it is unclear whether weight is a factor that influences prescription or a feature of prescription usage. Antipsychotic medication use also appears more prevalent in situations where nurses are the main support providers.

Antipsychotic medications are meant for a specific purpose: to treat individuals who are or at risk of psychosis, like that experienced by people who live with schizophrenia. For the most part, however, antipsychotics are prescribed as a mechanism to manage challenging behaviour in people with intellectual disabilities. This has occurred and continues to occur in some circumstances "despite no evidence for their effectiveness in treating challenging behaviours and considerable evidence of harmful side effects" (Emerson & Baines, 2010, p. 10).

The challenge for support providers is to apply appropriate assessment approaches to better understand and respond to challenging behaviours when they exist. This may include consulting behaviour specialists. Support providers must keep in mind that behaviour occurs in a context that includes both an individual's internal experience and external or environmental conditions. This means that components of the physical and social environments also need to be considered when trying to understand why challenging behaviours occur.

Mistreatment

There is widespread agreement that the prevalence of abuse in children and adults with intellectual disabilities is greater than in the general population. Unfortunately, abuse often comes from the hands of those who are assigned to provide care, support, and protection.

Though abuse of individuals with intellectual disabilities is no longer an accepted standard (as it was through much of history), it nonetheless continues to occupy a place in the dark corners of the disability world. In one study, Waldman, Swerdloff, & Perlman (1999) found that children who are abused are four times more likely to have intellectual disabilities than non-abused children. In another study, Verdugo, Bermejo & Fuentes (1995) found that 11.5% of children with intellectual disabilities had some evidence of mistreatment by age 19, compared with 1.5% of children without intellectual disabilities. In a more general study, Crosse, Kayey, & Ratnofsky (1993) found that children with disabilities are almost two times more likely to be sexually abused than children without disabilities. Though mistreatment is likely the result of a convergence of multiple factors, factors that appear to place individuals with intellectual disability at greater risk are:

- The view that people with intellectual disabilities are "less human" and therefore less valuable (or simply that they are lesser valued human beings)
- Physical and social isolation/segregation or marginalization, and the societal perception of differentness
- Lack of personal empowerment or ability/opportunity to influence others or circumstances
- Dependence on caregivers and support providers
- Learned compliance—people with intellectual disability are characteristically expected to do as they are told, to acquiesce to the requests, demands, and commands of others
- Physical defencelessness—people with intellectual disabilities who are dependent on others often have no recourse to defend themselves, to run, or to make other choices that will reduce the likelihood of mistreat-

ment

- Limited opportunities to develop social skills and resources needed to prevent or escape mistreatment
- Unwillingness by others to believe information from the mistreated person with disability or unwillingness to act on news of mistreatment—cultures of silence and inaction can develop among support and health care providers that function to tacitly approve and maintain mistreatment of vulnerable persons
- Limited communication skills—the individual with intellectual disabilities may not be able to speak or may have very limited word skills
- The inability of the individual with intellectual disabilities to differentiate between normal and unacceptable behaviour by others—individuals with intellectual disabilities are at risk for exploitation and sexual abuse because of limited or absent sex education, for example
- Limited cognitive abilities, increasing risk for mistreatment by people who misinterpret lack of understanding for *non-compliance*, and by people who are impatient or who see little personal risk in mistreating people who are at a cognitive disadvantage
- Behavioural challenges or overly compliant behaviour by the person with disability
- Stressful working or living conditions with limited resources and supports—for example, health care professionals or support providers responsible for supervising an unreasonably large number of individuals, workers not sufficiently prepared or supported to help individuals with challenges, or a socially isolated parent who is unable to cope with the 24-hour requirements of his or her son or daughter
- Absence of exemplary role models—when capable and caring colleagues, managers, family members, or friends are absent, inappropriate behavioural responses are more likely to be accepted and normalized within a specific environment
- Insufficient education and lack of supervised practice and feedback
- Lack of effective and enforced policies and procedures. Abusive behaviour is more likely to occur in workplace environments where there are no formalized expectations, requirements, or guidelines that support appropriate behaviour and deter inappropriate or abusive behaviour. Abusive behaviour is also more likely to occur in environments with appropriate policies and procedures when compliance with those policies and procedures is not effectively monitored and enforced (Manitoba Family Services and Housing, 2000).

Common Health Challenges: Mistreatment

Key Points for Caregivers

The foundation to providing appropriate support is respect for the right of individuals with intellectual disability to make informed choices and decisions about their own lives. *Informed* choices and decisions mean that people make their decisions based on a full and adequate understanding of all available options and their possible consequences. For supported persons with intellectual disability, it also means that they are able to discuss choices with people who are important to the decision and who genuinely have the best interests of the supported person in mind. When more severe disability exists, others must make decisions based on how they understand the supported person's wishes and values, still in the genuine best interests of that person.

Down Syndrome

Down syndrome occurs because of a chromosomal irregularity in human chromosome 21 (chromosomes contain genes). In the vast majority of cases, Down syndrome occurs spontaneously, rather than by inheritance. Overall, the incidence of Down syndrome is about one in every 700 to 1,000 live births, with the rate increasing to about one in 35 by the time the mother reaches age 45. Because most children are born to younger women, however, 80% of all Down syndrome children are born to women below the age of 35. In about 5% of cases, Down syndrome originates in the father, with paternal age past 50 to 55 believed to be a factor.

Although the reasons are not fully understood, people with Down syndrome experience accelerated aging (National Down Syndrome Society, 2012). It seems likely, however, that accelerated aging is largely due to genes on chromosome 21 that are related to the aging process. According to Moran and colleagues (2013), "the experience of accelerated aging can be seen medically, physically and functionally" (p. 4). Family members and support providers often report that individuals with Down syndrome just seem to slow down in their late 40s and 50s. Support workers should be conscious of and prepared for aging-related issues that commonly affect individuals with Down syndrome before most other people. One major aging-related issue is the potential development of early onset Alzheimer disease. Like the aging process, this disease has a gene located on chromosome 21, causing individuals with Down syndrome to be susceptible to the disease.

Whether age-related or otherwise, certain health conditions are especially common among individuals with Down syndrome. The following deserve the attention of support providers and health care professionals:

- ***Atlantoaxial instability (AI).*** AI occurs in 10% to 40% of individuals with Down syndrome and involves a looseness of movement at the point where the first and second cervical vertebrae meet. This creates risk for spinal cord injury. Some experts believe that this risk necessitates curtailment of contact sports for individuals with AI. Screening for non-symptomatic AI is an important consideration for health care professionals.
- ***Congenital heart defects.*** While only 0.8% of children in the general population have congenital heart defects, 30% to 60% of children with Down syndrome are born with heart defects (Forster-Gibson & Berg, 2011).
- ***Thyroid disease.*** Individuals with Down syndrome have a greater prevalence of thyroid disorders and are more likely to contract thyroid disorders at an earlier age than the general population, with 15% to 50% being hypothyroid (Forster-Gibson & Berg, 2011).
- ***Osteoporosis.*** The prevalence of osteoporosis, or brittle bones, in the population of individuals with Down syndrome is uncommonly high. In addition to Down syndrome itself, accompanying features (where they occur) such as small body size, delayed puberty, early onset menopause, and hypogonadism (undersized testes) are contributing factors in the development of osteoporosis.
- ***Alzheimer disease.*** Alzheimer disease or Alzheimer-like neuropathology has a sweeping effect on the Down syndrome population, with as many as 50% of individuals affected by the age of 60. As mentioned,

a genetic marker for Alzheimer disease is found on chromosome 21, meaning that people with Down syndrome are predisposed to Alzheimer disease.

- ***Leukemia.*** Childhood leukemia affects about 1% of individuals with Down syndrome. The risk for leukemia is 15 to 20 times greater than for individuals in the general population.
- ***Dental problems.*** Children and adults with Down syndrome commonly experience a variety of dental problems: delayed eruption of teeth, atypical sequence of eruption, missing teeth, enamel deficiencies, bruxism (teeth grinding), and periodontal (gum) disease. This suggests the importance of professional dental and periodontal care.
- ***Vision problems.*** Refractive errors are prevalent in individuals with Down syndrome, as are strabismus and nystagmus. Regular vision screening and optometric/ophthalmologic care is indicated.
- ***Other health problems.*** Drainage problems of the Eustachian tube (the tube that connects the middle ear to the back of the nose) and sinuses, scoliosis (curvature of the spine), gastroesophageal reflux, and seizure disorders are overrepresented in individuals with Down syndrome (Horwitz et al., 2000; Moran et al., 2013).

While Down syndrome is commonly accompanied by a variety of challenging medical complications, the advent of antibiotics and advances in medical procedures mean that many physical problems can be corrected or effectively treated. Because of these advances, the life expectancy of individuals with Down syndrome has improved dramatically.

Older People with Intellectual Disabilities

Like everyone else, people with intellectual disabilities experience health problems that are related to aging. However, older people with intellectual disabilities have higher rates of respiratory disorders, arthritis, hypertension, urinary incontinence, immobility, hearing impairment, and cerebrovascular accidents (strokes). Though the signs and symptoms of dementia are the same as those experienced by people without intellectual disabilities, dementia tends to be recognized later if it occurs. This may be due to support providers and health professionals confusing signs and symptoms of dementia with intellectual disabilities. It may also be due to the capacity of highly structured and routine environments, like those in community living situations, to mask emerging difficulties.

Note: *Dementia* is an umbrella term used to represent a cluster of symptoms that can be due to a variety of brain disorders (see Chapter 3). The symptoms include loss of memory, judgment, and reasoning, as well as changes in mood and behaviour. Functioning across everyday activities is impaired. It is important however, that support providers and health care professionals are aware that other conditions can produce symptoms similar to dementia. These can include depression, thyroid disease, infections, and drug interactions (Alzheimer Society of Canada, 2011). All of these need to be considered by health care professionals when there is concern about dementia or dementia-like features.

Impact of Support Providers on Health Status

It is important for support providers to work with family members and to keep them or appointed guardians informed (for example, a family member who has been given substitute decision-maker status for an adult brother or sister.) In addition to simply being good, respectful practice, it may be a legal requirement to discuss health issues, plans, and potential actions with loved ones, and obtain consent for particular procedures.

With that understanding, support providers can have an impact on maintaining and improving health status by:

- Arranging health care screening for potential health problems, and particularly for health problems that occur more often in people with intellectual disabilities (for example, vision and hearing screens, as well as screens that are commonly recommended for all people at particular ages)
- Preventing or limiting the spread of infections by regularly and strategically washing their hands and sneezing into their sleeve (support providers should stay away from the workplace if they are ill)
- Using proper feeding and drinking techniques when assisting individuals with severe neuromuscular impairment and dependency needs, to decrease the risk of aspiration and aspiration pneumonia
- Promoting fitness and a heart-healthy lifestyle with attention given to exercise/activity and nutrition (with the guidance of appropriate health care and fitness professionals, and with attention to limitations imposed by some conditions)
- Knowing about and attending to the special dietary needs of individuals with disorders that require dietary modifications (such as phenylketonuria), with the guidance of appropriate health care professionals
- Ensuring that immunizations and immunization records are up-to-date
- Enabling access to the same health promotion information as other members of the general population through
    - Modifying health promotion information as needed to promote understanding, with the assistance of public health professionals
    - Providing opportunities to practice a healthy lifestyle
- Knowing, monitoring, recording, and reporting effects and side effect of medications; if giving medications is a recognized responsibility, giving them in the prescribed manner and in a safe and reliable way that conforms to best practice policies and procedures; arranging for regular medication reviews
- Recognizing that all behaviour is communication and that behaviour can communicate meaningful information about an individual’s health, which is particularly important when working with individuals with severe disabilities and others who do not speak, or who have limited speech (for example, self-injurious behaviour such as wrist biting or head banging is commonly associated with pain in people with severe disabilities, when it has not occurred before)
- Following or helping to improve existing policies and procedures, and obeying legal obligations related to the treatment of people with intellectual disabilities
- Participating in ongoing education programs that teach how to work with people with challenging behaviours (when they exist) in an effective manner, with attention to respect and dignity

Health Promotion

The World Health Organization (2000) has stated that people with intellectual disabilities and their support providers need appropriate and ongoing education about healthy living practices. This information has commonly been inaccessible to many people with intellectual disabilities because of their dependency on others, and because of limited ability to understand, integrate, and independently act on healthy lifestyle information.

Gaining the attention of people with intellectual disabilities and their support providers is a central health promotion strategy. According to the U.S. Surgeon General, this means that healthy lifestyle information needs to be accessible, discussed, practised, and reinforced in the places where people with intellectual disabilities live, work, learn, and socialize (U.S. Department of Health and Human Services, 2002). Toward that end, health promotion planning requires the conscious, deliberate inclusion or targeting of people with intellectual disabilities and the development of strategies that better promote understanding and intended action by people with intellectual disabilities and their support providers. The World Health Organization suggests adapting existing self-care and wellness programs to fit the needs of individuals with intellectual disabilities. Depending on specific needs, this may mean using assistive technology and different forms of media to imbed learning and reinforce healthy behaviours. It may also mean using a no-fail approach that includes reducing complex information into its more easily understood component parts and teaching in an incremental way until desired learning is established.

Health Promotion

Key Points for Caregivers

Men and women with intellectual disabilities often lack the skill and opportunities to independently practise healthy living. Support providers and health care professionals are important to maintaining and improving health of people with intellectual disabilities through healthy living practices. This means that it is important for support providers and health care professionals to locate or develop best practice health promotion programs and then apply those programs. This gives people with intellectual disabilities the same opportunities to live healthy lives as other citizens.

Conclusion

In this chapter we have discussed the disparity in health status and lifespan between people with intellectual disabilities and the general population. For a small proportion of individuals with intellectual disabilities, health problems and reduced lifespan can be attributed to conditions associated with specific disorders, which can co-occur with or cause intellectual disabilities. For the most part, however, disparity in health status and reduced lifespan can be attributed to external factors that limit access to health care, or health care that is inappropriate or not equal to that received by most of the general population.

After the discussion of external factors affecting health status, we presented a discussion of issues and health problems that are particularly common to persons with intellectual disabilities. This included a discussion of the substantial vulnerability to mistreatment that many people with intellectual disabilities experience, and a specific discussion of Down syndrome and other health problems that occur more frequently. Accelerated aging was said to affect people with Down syndrome, but the entire population of persons with intellectual disabilities was also described as experiencing higher rates of many aging-related disorders and limitations.

Because of the high proportion of people with intellectual disabilities who require medications, and often multiple medications (polypharmacy), we have stressed the importance of safely providing and then monitoring the impact of medication use. The roles and responsibilities of support and health care providers received attention throughout the chapter, with the understanding that both groups are important to maintaining or improving the health of individuals with intellectual disability. Health promotion has been discussed as a particular strategy for maintaining and improving health that until now has largely been inaccessible to people with intellectual disabilities.

Chapter Audio for Print

This chapter contains a number of short audio clips. If you are reading this in print, you can access the audio clips in this chapter by scanning this QR code with your mobile device. Alternatively, you can visit the book website at opentextbc.ca/caregivers and listen to all the audio clips.

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CHAPTER 5: WHEN THE PROBLEM IS PAIN

Assessing for pain

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Introduction

Just like all people, individuals with intellectual disabilities experience pain. People with intellectual disabilities experience chronic pain related to medical conditions such as arthritis, cerebral palsy with significant spasticity, heart conditions, migraines, toothaches, earaches, infections, and other health issues. They experience pain related to traumatic injuries such as falls, accidents, broken bones, bruising, and injury from violence perpetrated against them. Some health condition interventions such as surgery or assessment procedures may be intrusive and painful. Medical assessments and treatment interventions can be scary and painful for any person, but they can be especially frightening for an individual with both intellectual disabilities and mental health challenges. Medical assessments and interventions often lead to an increase in anxiety, and sometimes aggressive behaviour, when individuals don't understand what and why certain events are happening (McKenzie, Smith & Purcell, 2012).

According to McCaffrey (1968), pain is whatever the experiencing person says it is and exists whenever he or she says it does. But a problem arises when individuals cannot report what is happening to them. The majority of individuals with intellectual disabilities are able to give some account of the pain they are experiencing, but the descriptions of localization of the pain and the potential origins of the pain can be difficult for some to articulate (Findlay, Williams & Scior, 2014; Hennequin, Morin, & Feine, 2000). Individuals who lack expressive language and have limited comprehension of language can usually only articulate their distress through changes in behaviour and facial expression, so pain must be assessed using a combination of behavioural cues and proxy information (information provided by others) (Davies & Evans, 2001).

Ethical Principles for Addressing Physical Health Conditions and Assessing Pain

The ethical principles of beneficence (the duty to benefit another) and non-maleficence (the duty to do no harm) oblige health care professionals, caregivers, and direct support staff to provide medical care for health problems and pain management and comfort to all individuals, including those who are unable to speak for themselves (Herr et al., 2011). The principles of justice (the equal treatment of individuals) and respect for human dignity also require support workers to do the best for individuals in their care.

The Hierarchy of Pain Assessment Techniques

Pain assessment techniques should follow a logical progression or hierarchy such as the one devised by Herr and colleagues (2011).

Obtain self-report. Get as much self-report of pain as possible. This may be a simple *yes* or *no* head nod or vocalization. It could include pointing or hand grasps or eye blinking. If a self-report is not possible, state the reason and proceed with assessment.

Search for potential causes of pain. Does the individual have arthritis or other chronic medical conditions that could be causing pain? Has the person experienced a trauma that would cause pain or has he or she experienced surgery or treatments such as wound care, blood tests, rehabilitation activities, or positioning/turning that are normally known to cause pain? Does the person show a significant change in behaviour such as signs of trouble with breathing, fainting, or change in bowel movements or passing urine?

Observe the person's behaviour. Use valid and reliable behavioural pain measurement tools. Look for a change in the individual's normal behaviour patterns, such as a normally outgoing person becoming more withdrawn, or a quiet, passive person starting to strike out aggressively, or a person engaging in self-injurious behaviour that is not typical (Bosch, 2002; Carr & Owen-Deschryver, 2007). Sleep and apparent sedation do not necessarily rule out a person experiencing pain. It is important that the assessment for pain involves the caregiver or staff person with the greatest knowledge of the person and his or her regular behaviours.

Obtain proxy reports of pain and behaviour/activity changes. Credible information can be obtained by proxy (from family members, parents, unlicensed or professional caregivers) who know the individual well. Parents and consistent caregivers are often the best sources of reliable information to assist with pain assessment. These individuals may have direct knowledge of how the person has responded to painful or illness-related situations in the past. They may be able to pick up on subtle signs that a new caregiver may not notice. Combine proxy information with direct observation of the individual and a thorough health assessment and examination. Proxy information does not take the place of a thorough physical, mental, and diagnostic workup.

Attempt a trial of pain relief medication or comfort measures. If mild or moderate pain is suspected, try comfort measures and non-opioid (non-narcotic) medications such as acetaminophen or ibuprofen every six hours for 24 hours. If behaviour improves, assume pain was the cause. For severe pain, a low-dose short-acting pain reliever such as hydrocodone or morphine should be given as a one-time dose under the direction of a physician to see if it brings relief. If so, a routine of regular pain medication may be ordered to manage pain. If pain or distress is not relieved after a reasonable pain relief trial with medication, then further assessment is required to identify the potential problem. In individuals with intellectual disabilities it is important to start with a lower dose of medication and work up to an effective dose, as these individuals may have greater sensitivities to medications. Go slowly, but the ultimate goal is to treat the pain effectively.

The Hierarchy of Pain Assessment Techniques

Key Points for Caregivers

Hierarchy of Pain Assessment

1. Obtain self-report.
2. Search for potential causes.
3. Observe behaviours.
4. Obtain proxy reporting.
5. Attempt trial of pain medication.

Guiding Principles Pain Assessment

People with intellectual disabilities have been cognitively impaired since birth or early childhood, and their intellectual disability continues throughout their lifetime (Herr et al., 2011). Intellectual disabilities can be accompanied by physical disabilities as well (Bottos & Chambers, 2006). An IQ of 50 to 70 indicates mild cognitive impairment and represents 85% of the population of people with intellectual disabilities. The majority of these individuals are verbal and usually acquire academic skills to the level of Grade 6. Most can self-report on their pain and the circumstances related to their pain. Individuals with an IQ below 50 have moderate, severe, or profound cognitive impairments. The Faces Pain Scale—Revised (see figure 5.1) can be used for those with suspected mental age greater than five years of age (Goodenough et. al., 1999).

Bottos and Chambers (2006) report that both children and adults with intellectual disabilities have higher tolerance for pain experiences when compared with healthy individuals. This may be related to challenges in recognizing and communicating pain to others. People with intellectual disabilities have been observed carrying out normal daily activities even when they have been seriously injured. Children and adults with intellectual disabilities often have medical conditions that require ongoing treatment or regular procedures and investigations that are associated with pain. Caregivers, family members, and professional caregivers need to regularly assess for the presence of pain, its location, and its severity. Once pain is identified, it needs to be treated and comfort measures provided.

Individual behavioural responses to pain vary from an increase in activity, such as pacing and vocalizations, to dampening of behaviours, such as becoming quieter and isolating from others. Although there have been some reports of differing sensitivities to pain (Foley & McCutcheon, 2004), most children and adults with intellectual disabilities do have intact sensory function (Symons, Shinde, & Gilles, 2008), which means they feel pain. However, people with intellectual disabilities may not express pain in the ways others do, and therefore it is important for caregivers to understand an individual's specific response to pain (Cheetham, 2001; Chivell, 2001; Temple et al., 2012; McGraft et al., 1998). Neurological perception and motor and/or communication abilities of an individual with intellectual disabilities can create challenges for others to effectively recognize that the individual is in pain. This can result in under- or overestimation of pain, which is why it is important to have people who know the individual well involved in the pain assessment and treatment process.

Behavioural Pain Assessment Tools

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Fig. 5.1 Wong-Baker FACES® Pain Rating Scale

According to Keck and colleagues (1996), children and adults, including those with intellectual disabilities, can point to the face on a pain scale that indicates their pain level. Individuals who can count and understand numbers can use the number scale, and those who can read can successfully use the word scales. The individual needs to comprehend the relationship of the scale to his or her experience of pain. The picture faces are often preferred as pain indicators and have been found to be successfully used by people with moderate and severe cognitive disabilities. Identifying possible causes for the pain and developing a treatment plan for most individuals with severe and profound levels of disability will also require proxy information and a thorough physical assessment. Although the Faces Pain Scale can indicate the presence of pain, it cannot identify the cause or location of pain.

Individualized Numeric Rating Scale

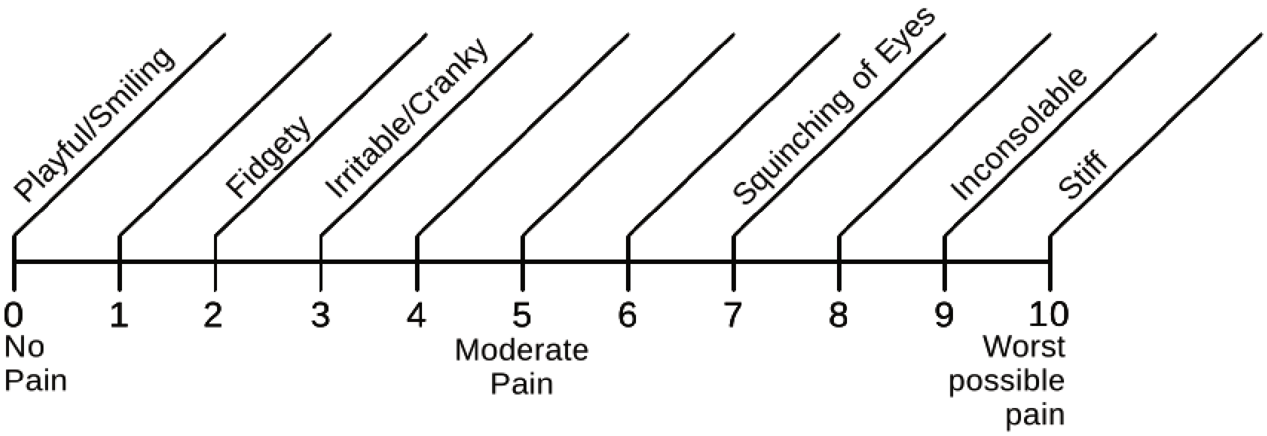

Fig. 5.2 Individualized Numeric Rating Scale

The Individualized Numeric Rating Scale (Curley, 2010) has primarily been used to assess pain in children with profound intellectual disability who are unable to use words to express pain (see the figure 5.2). These individuals depend on parents or caregivers who know them extremely well to report on their levels of pain. Several studies have demonstrated that parents of children with intellectual disabilities can describe their child's pain indicators (Carter, McArthur, & Cunliffe, 2002; Hunt et al., 2003; Voepel-Lewis, Maliviya, & Tait, 2005).

Care must be taken when transferring the use of the Numeric Rating Scale to adults and to people who do not have a consistent relationship with the individual with severe and profound intellectual functioning. Ideally, the setting should have some sort of documented health history of the individual, whether that is an institution, group home, assisted living, with family members or foster caregivers, or independent with supports. If the parents of the individual are still living and have regular contact with their son or daughter, they can provide a health history and their child's individual response to pain, health challenges, and visits to the doctor, dentist, and other health care providers. This information is valuable for helping the caregiver assess pain.

The Individualized Numeric Rating Scale is typically used in acute health care settings where the individual is receiving surgery, is in intensive care, or undergoing procedures known to be extremely painful, such as caring for severe burns. The parents or consistent caregiver are asked to fill in the scale with behavioural indicators of pain (Solodiuk et al., 2010). To do this they must have personal knowledge of the person when they are well and experiencing no pain. They must also have personal knowledge of behavioural indicators when the person has mild pain (headache, stomach ache), moderate pain (earache, toothache), or severe pain (broken bone, severe traumatic injury, post-surgery). The scale is then filled in with that person's individual responses, such as rocking when in moderate pain, history of head punching when having experienced a previous punctured eardrum, etc. These behavioural indicators are then used to provide the optimal level of pain relief.

FLACC Pain Assessment Scale

The FLACC Pain Assessment Scale (Merkel et al., 1997) looks at five categories of behaviour in an individual:

(F) face, (L) legs, (A) activity, (C) cry, and (C) consolability. Each of the five categories is scored from 0 to 2, which results in a total score between 0 and 10. The higher the score on this instrument, the higher the pain (see Table 5.1).

Table 5.1 FLACC Pain Assessment Scale

	Scoring	**Scoring**	**Scoring**
Categories	**0**	**1**	**2**
(F) Face	No particular expression or smile	Occasional grimace or frown, withdrawn, uninterested	Frequent to constant frown, clenched jaw, quivering chin
(L) Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
(A) Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
(C) Cry	No crying (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
(C) Consolability	Content, relaxed	Reassured by occasional touching, hugging, or talking to, distractable	Difficult to console or comfort

Picture Resources for Identifying Emotions of Physical Distress

For individuals who have functional language comprehension but limited expressive language, pictures can often be used to indicate wants, needs, or signs of distress. The website of Do2Learn Educational Resources for Special Needs (http://www.do2learn.com) includes many resources and programs for people working with individuals with special needs, including pictures that can be used for identifying emotions of physical distress. Pictures can be found at http://www.do2learn.com/picturecards/printcards/2inch/imagegrids.

The pictures shown in figure 5.3 are samples of some of the images that may be useful for working with individuals with intellectual disability. Copies could be made and laminated for use in household, group home, school, or work settings. Alternatively, a binder could be compiled for each individual, with images that are useful for that person's communication with others.

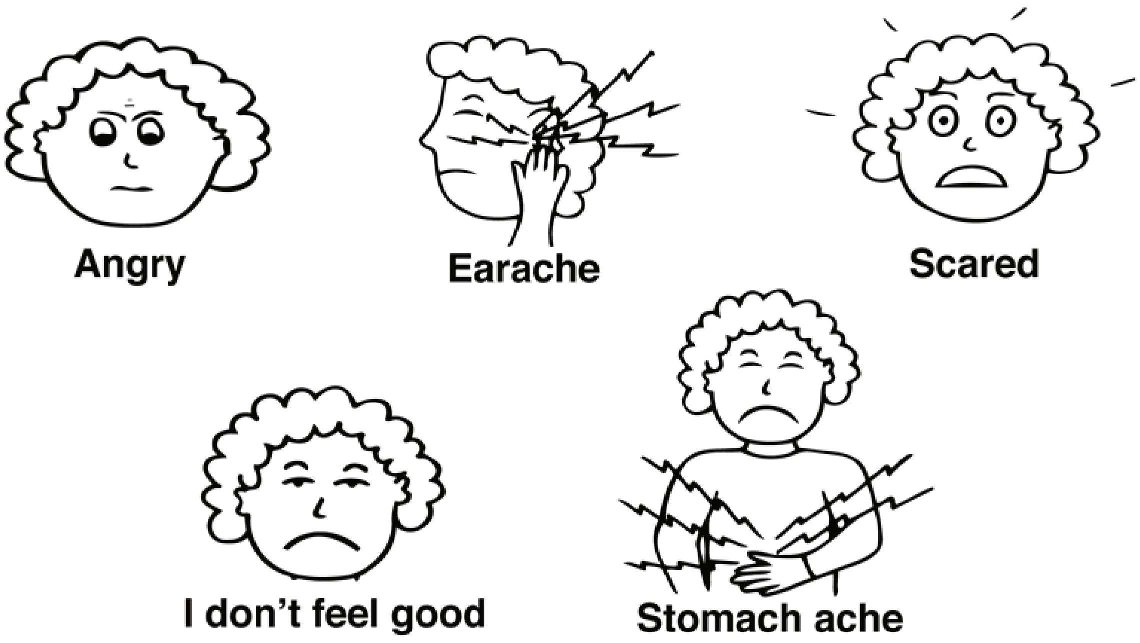

Fig. 5.3 Emotions of Physical Distress

Using the Disability Distress Tool

Meaningful communication with individuals with profound communication limitations depends on family members, caregivers, or support workers to identify and translate verbal, visual, or sound cues. Distress means many different things to different people (Regnard et al., 2007). Most people would agree that distress relates to more than just pain and physical discomfort. Many individuals with intellectual disabilities can give cues that they are distressed but may not be able to clearly communicate the source of their distress. This is most important for the individual who experiences cognitive, physical, and mental health challenges. Most distress cues are identified as deviations from the individual's normal way of being in the world. For this reason, it is important to identify the characteristics of an individual when he or she is content, so that caregivers can identify a change in verbal, visual, and sound cues when the individual is in distress.

Regnard and colleagues (2007) emphasize that while distress may be hidden, it is never silent. People with intellectual disabilities have differing abilities for receiving, understanding, remembering, and expressing themselves through use of verbal and non-verbal language. They depend on others to recognize and translate their specific language of signs and behaviours. The Disability Distress Tool (DisDAT) was designed by Regnard and validated by his research team to help caregivers recognize and respond to distress in individuals with intellectual disabilities (see Table 5.2). When using the DisDAT, it is critically important to document signs and cues when an individual is content to compare with signs and cues he or she displays when distressed.

Table 5.2 DisDAT. Most common signs and behaviours (cues) presented by individuals with disabilities when content and when distressed

Contented cues (signs and behaviours observed in person when content)	**Percentage presenting with these cues**	**Distressed cues (signs and behaviours observed in person when distressed)**	**Percentage presenting with these cues**
Smiles	80	Lifts hands to head	50
Vocalizes without prompting	70	Screams, wails	40
Has relaxed body/face	50	Withdraws	40
Laughs	40	Becomes quiet	30
Responds vocally to social interaction	40	Groans	30
Has bright eyes	40	Face is bright red	30
Makes eye contact	40	Body is rigid	30
Eyes move around	30	Looks tearful, sad	20
Gestures towards social partner (spontaneous and response)	30	Is restless	20
Is affectionate	30	Clenches and grinds teeth	20
Is quiet	30	Grimaces, face is distorted	20
Sits straight/upright	20	Body is slumped	20
Blows raspberries	20	Uses different tone in vocalization	20
Grimaces	10	Face is rigid	10
Grinds teeth	10	Curls into themselves	10
Head is upright	10	Is not smiling	10
Is involved in interactions and environment	10	Makes growling noises	10
Likes close proximity	10	Eyes widen	10
Makes sighs of contentment	10	Increases eye movement	10
Co-operates with interventions	10	Breathes shallowly	10
Taps feet to music	10	Has shortness of breath	10

Both people who know the individuals and those who do not know them are able to identify distress using the DisDAT tool. However, people who know an individual's specific signs and cues able to identify the distress earlier. (Distress is noted as a change from contented behaviours to behaviours that indicated distress.) Keep in mind that each person typically has his or her own language of distress. The DisDat is available online at http://prc.coh.org/PainNOA/Dis%20DAT_Tool.pdf

Pain and Health Care for Dually Diagnosed Persons

People with intellectual disabilities and mental illness deserve the same standard of care as all other individuals. This means they should have regular annual checkups with a physician, a dentist, and any other health professional who is regularly involved in their care, such as a physiotherapist or occupational therapist. Individuals may have one or more medical conditions that require more regular follow-up (for example, diabetes that requires monitoring by a physician every three months). Caregivers should expect and advocate for this level of care to ensure that complications related to disease processes are detected early. People with intellectual disabilities may require a longer appointment time and/or may feel more comfortable if a person they trust accompanies them to their appointments (see Chapter 4).

Unfortunately many people with dual diagnosis receive substandard care, perhaps because a health care professional holds prejudicial beliefs about individuals with intellectual disabilities, or simply because he or she does not know how to care for individuals with intellectual disabilities. If an individual has experienced diagnostic testing and surgical procedures in the past without adequate pain treatment, or didn't understand what was happening or what was expected, he or she may be fearful and anxious before health care visits. Similarly, when health care services have not recognized, treated, or managed an individual's pain well, the caregiver can leave the experience feeling the negative emotional impact (Findlay, Williams, Baum, Scior, 2014).

The gold standard for good pain assessment is to have the individual self-report symptoms as much as he or she is able before a proxy adds information. Caregivers should report regular behaviour, any changes that they have observed, and whether they have seen these responses in the past related to specific health care concerns.

None of this information takes the place of a thorough physical assessment and diagnostic workup by a health care professional. Ideally, clients should see health care professionals who know them well and who have the individual's health care history. In emergencies and in situations where the individual is in obvious pain or distress, they may see health care professionals they have never met before. This can be quite frightening and anxiety-provoking for many individuals, especially for those who also have mental health issues (see Chapter 3). Thus, it is important that the individual be accompanied to appointments or to the emergency department by a family member or caregiver who knows the most about the person, who can provide comfort, and who is trusted by the person. Many people with intellectual disabilities may require some anxiety medication or sedation for complex dental or medical procedures, so they really appreciate having someone with them who cares. Often an individual can be helped by distracting activities, ongoing conversations, a comforting object, or a promise of an enjoyed activity after a health care visit.

Conclusion

In this chapter we have discussed the experience of pain. Health care providers, direct support workers, and all those who care for and about individuals living with intellectual disabilities have an ethical duty to implement pain assessments with both verbal and non-verbal information. Often the main indicators that a person is in distress are behavioural cues and information from others. The progression or hierarchy of steps to assess pain are 1) obtain a self-report, 2) search for potential causes, 3) observe behaviours, 4) obtain information from others (proxy reporting), and 5) attempt a trial of pain medication. People may experience pain even when they are carrying out normal daily activities, and therefore a guiding principle is to involve those who know the person throughout the process of assessing and treating pain.

Five tools to assess physical pain have been explained: 1) the Wong-Baker FACES® Pain Rating Scale, 2) the Individualized Numeric Rating Scale, 3) the FLACC Pain Assessment Scale, 4) pictures for identifying distress, and 5) the DisDat. We have emphasized how dually diagnosed people require regular checkups that include thorough physical assessments and diagnostic workups. During complex medical procedures, caregivers can request that health care professionals provide anxiety medications. Caregivers can provide distracting activities or an enjoyable activity after the procedure. Assessing and responding when dually diagnosed people say or show that they are in pain is a critical element in supporting them toward living healthy lives.

Chapter Audio for Print

This chapter contains a number of short audio clips. If you are reading this in print, you can access the audio clips in this chapter by scanning this QR code with your mobile device. Alternatively, you can visit the book website at opentextbc.ca/caregivers and listen to all the audio clips.

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CHAPTER 6: BEHAVIOUR THAT HURTS

Self-injuring and aggressive behaviour

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Introduction

Caregivers can struggle with how to respond when people who live with both intellectual disabilities and mental illness express themselves through behaviours that are hurtful, either to themselves or to others. Unfortunately, challenging or problem behaviours such as self-injury and aggression are highly prevalent in individuals with dual diagnosis (Allen & Davis, 2007; Benson & Brooks, 2008; Lowe et al., 2007; Lloyd & Kennedy, 2014). As well as jeopardizing their own and others' physical safety, challenging behaviours can result in 1) isolation when individuals are denied access to community facilities (Emerson, 1995); 2) greater likelihood of chemical restraint (Webber, McVilly, & Chan, 2011); 3) more frequent admission to psychiatric units than the general population (Lunsky & Balogh, 2010); and 4) more restrictive interventions during hospital stays (Chaplin, 2011).

In some instances, when people engage in self-injurious and aggressive behaviours, their actions are related to pain (see Chapter 5), to a health-related disorder (see Chapter 4), or to escalating symptoms of a psychiatric disorder (see Chapter 3). In other instances, their actions may be triggered by stress (Charlot & Shedlack, 2002) or a lack of the social skills needed to cope with life events (Barnhill & McNelis, 2012; Waters & Healy, 2012).

Medications, particularly antipsychotics, are often prescribed despite mounting concern about their overuse (Edelsohn et al., 2014; Gormez & Varghese, 2014; Lunsky & Elserafi, 2012). When challenging behaviour is not caused by psychiatric disorders, treatment with psychiatric medication can even cause the behaviour to worsen (Allen & Davies, 2007; Valdovinos et al., 2005).

Clearly, it is important to investigate any possible links between challenging behaviours and physical health, mental health, and stress or social triggers. It is also important to collaborate with health professionals about prescribing medications that may help. However, first and foremost, when people are engaging in hurtful behaviour, these behaviours must be addressed. Although challenging behaviours may have started in response to identifiable concerns, they often persist long after the original concern has been resolved (May & Kennedy, 2010).

When individuals engage in behaviour that hurts it is helpful to focus less on the causes of the behaviour and more on what purpose the behaviour serves. Applied behavioural analysis is a treatment approach that investigates what purpose a behaviour may be serving and helps develop methods to change the behaviour with new ways of meeting an individual's needs (Behavior Analyst Certification Board, n.d.). In this chapter we provide an overview of applied behavioural analysis and then discuss strategies to help decrease self-injurious and aggressive behaviour.

Overview of Applied Behavioural Analysis

A widely accepted definition of applied behaviour analysis is that it is a systematic process of applying interventions grounded in learning theory to both improve behaviours and to demonstrate that the interventions are responsible for improving the behaviour (Baer, Wolf, & Risley, 1968). Extending from early work based on principles of behaviour modification, behaviour analysts use positive reinforcement to increase desirable behaviours, generalize learned behaviours, or reduce undesirable behaviours. One of the key tools that professionals in the field of applied behavioural analysis use on a regular basis is functional behavioural assessment.

Overview of Applied Behavioural Analysis

Key Points for Caregivers

People may hurt themselves (called self-injury) or other people (called aggression). Self-injury or aggression may occur because of pain, a health-related disorder, stress, as a symptom of a psychiatric disorder, or because a person lacks social skills. Medications may even make the problem worse. These possibilities must all be investigated. Challenging behaviour that starts for one reason may continue even when that reason is no longer there. Behavioural analysis looks at what needs are served by a behaviour and then finds other ways that people can meet those needs.

Functional Behavioural Assessment

Although most caregivers are not expected to implement functional behavioural assessments with their clients, understanding the thinking behind this tool can make an important difference in providing evidence-informed care. Morris (n.d.) identified the ABCs of functional behavioural assessments as *Analysis*, *Behaviour*, and *Consequence*. *Analysis* occurs when professionals direct the client to perform an action to identify existing or previous behaviour. *Behaviour* is the response from the client: successful performance, non-compliance, or no response. *Consequence* is the therapist's response "which can range from strong positive reinforcement (i.e., a special treat, verbal praise) to a strong negative response, such as 'No!'" (Morris, n.d.). When behavioural analysts implement functional behavioural assessments, these ABCs ground their thinking.

Functional behavioural assessments look beyond observable behaviour and examine what function the behaviour may be serving (Mauro, n.d.). Knowing what is valuable, important, and reinforcing to individuals can help caregivers support their clients toward alternative ways of behaving that will still meet client needs. Functional analysis of challenging sexual behaviours is discussed in Chapter 7.

Research with children and individuals living with autism spectrum disorders has contributed to our understanding of functional behavioural analysis, and people with dual diagnosis can benefit from insights generated from this research. One seminal study conducted with children sheds important light on why individuals would continue or maintain their challenging behaviours. Iwata and colleagues (1982, 1994) identified three variables or reasons why challenging behaviours were actually serving a valuable purpose. The first reason was that the behaviour resulted in *attention*. In the study, children were given toys to play with and told that an adult in the room had work to do. With each demonstration of challenging behaviour, the child was given attention, albeit socially disapproving attention, with comments such as “Don’t do that!” The second reason was that the behaviour afforded them an *escape* from demands. When children were given educational activities to complete, their challenging behaviours resulted in not having to complete the activity. The third reason was that the behaviour seemed to increase the sensory stimulation the children were experiencing when being *alone*. Motivation to continue the behaviour was believed to be linked to the feelings of self-stimulation that occurred. Self-stimulation is defined as behaviour that creates internal pleasure or removes displeasure without the involvement of any other person (O’Neill et al., 1997).

Subsequent research also supports these findings and extends our growing understanding of what behavioural analysts look for when implementing functional assessments. For example, Iwata and colleagues (1994) studied 152 individuals with developmental disabilities who demonstrated self-injurious behaviour over an 11-year period. Their findings indicated that negative reinforcement in the form of escape from demands or aversive stimulation accounted for 38.1% of the behaviours, the largest proportion of the sample. Positive reinforcement in the form of access to preferred stimulation such as attention, food, or materials, accounted for 26.3% of the behaviours. Automatic reinforcement of the senses, also known as autonomic sensory reinforcement, accounted for 25.7%. Automatic reinforcement is a type of reinforcement that creates a favourable result without any involvement from others (Cooper, Heron, & Heward, 2007). Multiple controlling variables (such as both escape and attention) accounted for 5.3% of the behaviours, and 4.6% were uninterpretable.

Similar results are found in numerous follow-up studies of functional analyses for self-injuring or aggressive behaviour (Beavers, Iwata, & Lerman, 2013; Hanley, Iwata, & McCord, 2003; Kurtz et al., 2003; O’Reilly, 1995). In short, people may be demonstrating challenging behaviour that serves the purpose of escaping from aversive stimulation, accessing preferred stimulation, or creating automatic sensory reinforcement. For example, individuals may want to escape from math work, house cleaning, life skills activities such as brushing teeth, stimulation that is too loud, work that is too difficult to complete, or even from a non-preferred texture. They may want to access preferred stimulation such as being with people they like, tasting food they enjoy, and participating in activities they believe are fun. Finally, they may want to create autonomic sensory stimulation to bring about a feeling of pressure (such as head banging), or the sound produced by the behaviour (such as hitting ears), or different sights (such as eye gouging), or tactile experiences (such as scratching and self-biting).

It may be useful to think of these behaviours as a form of self-expression and a way of communicating needs, such as “I want attention” or “I need a break.” Viewing challenging behaviours through the lens of behavioural analysis, self-injuring behaviour may indicate a need for sensory stimulation, and aggressive behaviour may indicate a need for social reinforcement.

Functional Behavioural Analysis

Key Points for Caregivers

Functional behaviour analysis helps us understand why people continue injuring themselves or being aggressive. Three common reasons for any behaviour are that it:

1. Provides an **escape** from something a person does not like
2. Provides **access** to something a person does like
3. Provides stimulation that a person can create when they are **alone**

When people need to escape from an activity that is difficult or unpleasant, providing a break may help. When they need access to something they value, such as favourite people, food, or activities, providing this access before challenging behaviour begins may prevent the challenging behaviour from occurring. When people are alone and they need stimulation, they can be given alternatives through opportunities for them to see, hear, smell, touch, and taste.

Topography of Behaviour

Having a familiarity with the vocabulary or terms used to describe behaviours demonstrated by individuals with dual diagnosis is important. One term used by behavioural analysts and other professional groups when implementing functional behavioural assessments or when devising behaviour intervention plans is *topography of behaviour*. *Topography* is a detailed description of the natural features of a geographical area. In other words, topography clearly describes what is there and what we see. A topographical description does not include interpretations of what is observed. For example, maps of a geographical area do not usually include commentary about whether the area is “good” or “bad.”

When topography frames a way of describing challenging behaviour, the same clarity of description and absence of judging value or imposing expectations is expected. For example, reporting that an individual was disrespectful does not describe what is there and what we can see. Descriptions such as “Terra refused to comply with a direction” provide clarity. Similarly, Webster (n.d.) illustrated two different topographical ways of reporting a tantrum. Wording could be “Dylan threw himself on the floor, kicked, and screamed in a high-pitched voice. He did not make physical contact with other individuals, furniture, or other items in the environment.” Different wording could be “Dylan swung his arms and struck other clients and staff, while screaming in a high-pitched voice” (Webster, n.d.). Although each of these reports describes a tantrum, the topographical elements of the descriptions provide critical information when assessing aggression.

Topography of Behaviour

Key Points for Caregivers

Challenging behaviours must be described and reported in detail so that others have a clear picture of what people are actually doing. Topography of behaviour, like topography of a geographic area illustrated in a map, describes only what is there and what we see. Topographies of behaviour do not judge value or include expectations.

Strategies to Help Decrease Self-Injurious and Aggressive Behaviour

Once functional behavioural assessments have been implemented to indicate the purpose a behaviour may be serving, and the topography of the behaviour has been described clearly and without judgment, caregivers can consider new ways to support individuals toward meeting their needs. In this section, we draw from the field of behavioural analysis to outline three approaches that can help decrease self-injurious and aggressive behaviour. The first addresses escaping from aversive stimulation; the second addresses accessing preferred stimulation; and the third addresses creating automatic sensory reinforcement.

Escaping from aversive stimulation. When individuals hurt themselves or others to escape from situations that are aversive, behavioural analysis interventions can be directed toward 1) making the behaviour no longer a way to escape (Escape Extinction, EE); 2) providing instruction to help make the situation less aversive (Skills Training, SK); or 3) finding an alternative way to escape (Differential Reinforcement of Alternative Behavior, DRAB) (Geiger, Carr, & Leblanc, 2010).

Accessing preferred stimulation. When individuals engage in challenging behaviour to access the kind of stimulation they prefer (such as attention from people, food, or activities), strategies can be directed toward other ways they can access these people and the things they enjoy (Functional Communication Training, FCT). For example, as part of an FCT approach, caregivers gave a card reading “I want to talk” to an individual demonstrating aggressive behaviour (Roscoe, Kindle, & Pence, 2010). By using the card instead of aggressive behaviour, the individual was able to access what was important to him, which in this case was conversations with others. In another example of FCT, caregivers taught an individual demonstrating self-injurious behaviour to ask, “Am I doing good work?” Each time the individual did this instead of hurting herself, caregivers provided her with 10 to 15 seconds of attention (Durand & Carr, 1991).

Creating automatic sensory reinforcement. When individuals engage in challenging behaviours, particularly behaviours that are self-injurious to create their own sensory reinforcement, finding the right strategy to help decrease the behaviour can be difficult. Since autonomic sensory reinforcement does not rely on other people, the reinforcement that caregivers are able to offer may not be meaningful. Identifying what might be pleasing about a behaviour that is hurtful to self or others is not straightforward. Questions must be asked about whether the pleasing stimulus is a physiologic effect, and if so, what is the feeling?

However, strategies that ignore the challenging behaviour and provide reinforcement when the behaviour does not occur for a specified period of time (Differential Reinforcement of Other, DRO) show promise. In one case where DRO effectively decreased a behaviour, caregivers set up a schedule for praising a boy when he decreased his skin-picking behaviour. The schedule included leaving the boy alone but entering the room regularly. Each time the boy did not engage in skin-picking, caregivers offered a token and praise such as “Good job not scratching” (Toussaint & Tiger, 2012).

Another strategy that can lead to substantial decreases in automatically reinforced challenging behaviour is environmental enrichment. This strategy begins with an assessment that identifies what items the individual prefers, and then ensuring that these items are made available. Research has shown this strategy can substantially decrease self-injury that is automatically reinforced (Lindauer, DeLeon, & Fisher, 1999; Smith et. al, 1993; Vollmer, Marcus, & LeBlanc, 1994). Environmental enrichment is the least labour intensive of all the strategies described in this chapter. No one is required to monitor individuals in order to implement the strategy; instead, the preferred items are made available in ways that provide an enriched environment. This approach may be useful when little time is available for individual attention. To successfully implement this strategy over longer periods of time, individuals need continued assessment for items/activities they still enjoy, those they have tired of, and new ones that could be added.

A final strategy simply makes the desired sensory stimuli freely available. For example, when an individual engaged in self-injurious hand mouthing, behavioural analysts hypothesized that his hand mouthing produced mouth stimulation, hand stimulation, or both. In response, they made Twizzlers (licorice-flavoured candy sticks), mouth guards, and hand stimulators freely available for mouth and hand stimulation (Piazza et al., 2000).

As the preceding discussion has illustrated, when caregivers are able to accurately identify what an individual finds stimulating about a challenging behaviour, they are more able to support them towards behaving in ways that do not focus on hurting themselves or others.

Strategies to Help Decrease Self-Injurious and Aggressive Behaviour

Key Points for Caregivers

Strategies to help decrease self-injurious and aggressive behaviours provide individuals with alternative ways to meet their needs.

1. When people need to escape difficult situations, strategies can prevent escape, can offer instruction to make the situation less difficult, or can offer an alternative way to escape.

2. When people want access to stimulation they like, such as food, activities, or attention from people, strategies can make these people and things available. Strategies can include:

    a. Card reading or saying “Help please” or “Break please” as an alternative to aggressive or self-injurious behaviour

    b. Presenting fewer or less difficult tasks for the individual to complete

    c. Breaking down larger or complex tasks into smaller steps

d. Providing help and prompts to the individual at regular and ongoing points of time, only reducing help when the individual shows that he or she has mastered the skill independently

3. When people want stimulation for their senses when they are alone, strategies can offer comparable ways to experience the sensations and feelings. An example of a strategy is substituting appropriate food treats to provide alternate sensations experienced during hand mouthing.

a. Regular scheduled praise from a caregiver, such as "Good job not …" when challenging behaviour does not occur within a specified period of time

b. Providing preferred items for the individual to interact with instead of engaging in challenging behaviour.

Conclusion

People may engage in self-injurious and aggressive behaviours because of pain, a health-related disorder, symptoms of a psychiatric disorder, medications, stress, or because they lack social skills. The behaviour may even continue or be maintained long after the problem that caused the behaviour been resolved. In this chapter, we have emphasized the importance of addressing these challenging behaviours and provided strategies from the field of applied behavioural analysis that can help decrease the behaviours.

Behavioural analysis is an approach that determines the purpose a behaviour serves or what value it might have to people, and then finds other ways to meet their needs. Functional behaviour analysis is a tool that can identify specific reasons why people would find it valuable to maintain self-injurious and aggressive behaviour. Common reasons are that the behaviour provides escape from aversive stimulations (unpleasant or difficult experiences), access to preferred stimulation (pleasant experiences often with people, food, and activities), and creates automatic sensory reinforcement (sensory stimulation when the person is alone). Topographical descriptions are clear detailed descriptions of the behaviour we can see. When topography of behaviour is explained in functional behaviour analysis, no judgments about value are included.

Knowing that people might be engaging in challenging behaviours to escape, caregivers can try strategies to prevent escape, to offer instruction and help, or to find alternative ways to escape. Similarly, knowing that people might want access to people, food, and activities they like, caregivers can try to make these people and things more available. Finally, knowing that people might value stimulation for their senses when they are alone, caregivers can look for ways to offer pleasing experiences with sight, sound, smell, and touch.

Chapter Audio for Print

This chapter contains a number of short audio clips. If you are reading this in print, you can access the audio clips in this chapter by scanning this QR code with your mobile device. Alternatively, you can visit the book website at opentextbc.ca/caregivers and listen to all the audio clips.

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CHAPTER 7: SEXUALITY

Promoting healthy sexual expression

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Introduction

Individuals with intellectual disabilities experience difficulty in interpreting behavioural cues within their social environments. This may in turn create negative outcomes for their expression of sexuality (Meany-Tavaras & Gavidia-Payne, 2012). People with intellectual disabilities are overrepresented as both victims and perpetrators of sexual offences (Hogg et al., 2001; Lambrick & Glaser, 2004). According to Szollos and McCabe (1995), 50% of females with intellectual disabilities will be sexually assaulted in their lifetime, and males with intellectual disability are more likely to be sexually abused than other males.

One of the most significant factors in the sexual victimization of individuals with intellectual disabilities is their knowledge deficit regarding acceptable behaviour. More specifically, they may have limited sexual knowledge in the areas of consent and what constitutes appropriate sexual contact (Galea, Butler, & Iacono, 2004; Gust et al., 2003). They can find it difficult to assert their own opinions and they may give in to the suggestions or directions given by others, particularly when expressing their sexuality (Hayashi, Arakida & Ohashi, 2011).

People with intellectual disabilities depend on family members and service providers to teach them how to appropriately express their sexuality, which is a critical aspect of social competence. Many individuals with intellectual disability need ongoing education about sexuality, particularly self-protective strategies, so that others will not take advantage of them.

However, depending on past life experiences, the kind of education needed varies from one person to another. Individuals with a mild to moderate disability who live with their own or a foster family may have attended sexual health classes as part of the social skills training provided in schools, vocational programs, and sheltered workshops. Those with a severe or profound disability who live in group homes or institutions surrounded by professional caregivers and others like themselves will have had fewer educational opportunities.

Those with more social skills training, more exposure to different life experiences, and more opportunities to function socially can be expected to demonstrate more social competencies (Abbott & McConkey, 2006; Simpson, 2010). Despite the diverse educational needs of individuals with intellectual disabilities, supporting them to show healthy expressions of their sexuality is important. In this chapter we discuss three critical areas that should be considered when providing sexual education support: discussion topics, understanding boundaries, and differentiating between challenging behaviours and sex offending behaviours.

Discussion Topics for Sexual Education Support

Although major gains have been made in the last two decades in normalizing, including, and integrating people with intellectual disability into community settings, their sexual health continues to be an overlooked area (Scotti et al., 1996; Thompson et al., 2014). Historically, in many countries intellectual disability or “feeble-mindedness” was considered hereditary, and individuals identified as *mentally defective* were sterilized without their knowledge to prevent procreation (Grekul, Krahn, & Odynak, 2004). Today, sexual education programs for people with intellectual disabilities are becoming more commonplace and researchers are beginning to understand the kinds of discussion topics that are most valuable.

Critical discussion topics that can help individuals begin to understand their own personal sexuality are puberty, menstruation, menopause, masturbation, relationships, protective behaviours, sexuality, safer sex practices, contraception, pregnancy and birth, sexual health screening tests, sexually transmitted infections, and legal issues regarding sexuality (Butler, Leighton, & Galea, 2003). Other topics are body grooming and cleanliness, first impressions in speaking to your partner, communication training, self-assertiveness training, a sense of space between participant and others, manners in public spaces, sexual harassment, stalker victimization, male–female relationships, and differences between male and female bodies (Hayashi, Arkida, & Ohashi, 2011). While support workers and family members themselves may not be the one delivering sexual education programs, it is helpful for all those involved to initiate discussions about these topic areas, invite further questions, and provide ongoing guidance.

A controversial sexual education topic that also needs to be discussed is parenting. Both family members and caregivers have expressed concern about parenthood and marriage for adults with intellectual disabilities (Oliver et al., 2002). Parents with intellectual disabilities represent one of the most vulnerable parenting groups (Booth & Booth, 2005). Most concerns relate to neglect or emotional abuse, with 40% to 60% of parents with intellectual disabilities having their children removed by child protective agencies because they failed to meet the standard of good enough parenting (Cleaver & Nicholson, 2005). Researchers believe that these numbers could be lowered if parents with intellectual disabilities had adequate supports and education (Cleaver & Nicholson, 2005; Murphy & Feldman, 2002). Specific areas these parents need help with are generalizing information from one setting to another; knowledge about normal childhood development and the care needs of infants, children, and adolescents; and knowledge about how to play with and show appropriate affection to their children (Wilson et al., 2013).

According to the International Association for the Scientific Study of Intellectual Disabilities (2008), parents with intellectual disabilities need both parenting skill education and a strong social network. When parents, especially mothers, are surrounded by helpful family members, friends, and professionals, they develop an increased capacity to care for their children (Guinea, 2001; Koeske & Koeske, 1990; Wilson et al., 2013). Unfortunately, the reality is that these parents often find themselves with limited social and environmental support (Mayes, Llewellyn, & McConnell, 2006).

Discussion Topics for Sexual Education Support

Key Points for Caregivers

Sexual health is often overlooked in individuals with intellectual disabilities. They are very vulnerable to sexual abuse and may not understand what consenting to sexual activity means. They may not know how to express their sexuality. Sex education programs often include important discussions of normal expressions of sexuality such as masturbation, relationships, contraception, sexually transmitted diseases, and safe sex practices. These kinds of topics must also be part of the everyday conversations that take place between intellectually disabled individuals and the people in their lives. When individuals with intellectual disabilities are parents, they need a network of people around them and opportunities to learn about children's development and showing appropriate affection to children.

Understanding Boundaries

Boundaries are the limits in relationships within which we feel psychologically safe (Kent, 2012). Individuals with intellectual disabilities may have difficulty understanding the boundaries that are expected in conventional social relationships. For example, they may interrupt, have difficulty taking turns or waiting for assistance, and steal other's belongings. When interacting with caregivers, they may express sexual feelings through behaviours such as intruding into the caregiver's personal space, requesting to be a boyfriend or girlfriend, and attempting to kiss or touch in a sexual manner. These behaviours leave caregivers feeling confused and uncomfortable. A fitting response is for staff groups to consistently and immediately provide straightforward feedback that these behaviours are not acceptable.

Similarly, individuals with intellectual disabilities may demonstrate inappropriate sexual behaviours in public. Examples are masturbation, genital exposure, inappropriate sexual touching, and embracing others too closely (Bielecki & Swender, 2004; Nagahama, 2003; Yamamoto, 1991). They may walk into public areas naked, touch others, or allow themselves to be touched. They may grab others roughly to get attention or indicate a personal need. In individuals with dual diagnosis, these overt sexual demonstrations may indicate an escalating psychiatric disorder. Rather than simply viewing these behaviours as distasteful, it is vital for caregivers to document, report, and discuss them with other staff members and health professionals.

It is important to hold these individuals accountable for their behaviour. When behaviours seriously violate the boundaries and feelings of psychological safety for caregivers and others, it is important to ask what would happen to those who are not intellectually disabled if they engaged in these same behaviours. If the answer is that they would be charged with sexual or physical assault, then involving the police must be considered. Treating people with disabilities differently suggests that they are not responsible for their actions and thus not real members of society.

Caregivers model the process of setting boundaries through their own actions. They can use anatomical rather than slang or baby-talk words during discussions related to sexuality. They should avoid flirting, telling or listening to sexual jokes, and swearing or offensive language (Cooper, 2012). They can show respect for modesty by performing personal care in private rather than public spaces. Simple acts such as knocking before entering someone`s room and keeping doors open during private discussions communicate subtle cues about acceptable behaviour. Instead of allowing a non-verbal person to grab others in an aggressive way when he or she wants something, redirecting the action by demonstrating a more gentle way to reach out can be helpful. As previously mentioned and in accordance with any applicable agency policy, caregivers must confront and report inappropriate expression of sexual expression to their supervisors or even the police.

Providing Resources

For individuals with limited language or who use pictures as part of their communication strategies, signs and/or picture cards for *yes*, *no*, *don't touch*, and *stop* are useful. As discussed in Chapter 5, prepared cards illustrating common needs and feelings are available at the Do2Learn (n.d.) website, http://www.do2learn.com.

Another useful resource to promote awareness about boundaries is the *Circle of Relationships* activity (Walker-Hirsch & Champagne, 1991). Here, different levels of intimacy and appropriate social behaviours are indicated by colour groups (see Table 7.1). A hand-out of Table 7.1 could be provided to participants, who can then be invited to link names of people they know to a colour group.

Table 7.1 Circle of Relationships activity

Colour Code and Name	**Description**
Purple Private Circle	You are important and you will decide who can touch you. No one should touch you unless you want to be touched. Sometimes people in your Blue, Green, Yellow, Orange, or Red Circles will try to get too close to you. You need to say STOP. No one touches you unless you want to be touched and you do not touch other people unless they want to be touched.
Blue Hug Circle	It is a mutual decision to kiss and hug and be close. If you do not want to, you must say STOP. Sometimes you may not feel like being touched. This does not mean that you are no longer close with your partner, but only that you are not feeling loving at that moment. Your partner can say STOP to you too.
Green Faraway Circle	Sometimes a friend may want to be closer to you than you want. You just explain to your friend and say STOP. You may give a faraway hug only on special occasions. You can say "You are not in my Blue Hug Circle."
Yellow Handshake Circle	Sometimes someone whose name you know may ask for a Faraway Hug. You can say NO. No one can touch you unless you want to be touched. You can use a handshake to greet this person if it feels right for you.
Orange Wave Circle	Wave to an acquaintance who is too far away for a handshake. Sometimes children will want to hug and kiss you, but you can say NO. It is best to wave to children. Children do not know as much as you, so it is best to show them correct behaviour.
Red Stranger Circle	Some people stay strangers forever. You may talk about business to a stranger who is a community helper. Other strangers do not talk to you or touch you. If a stranger touches you after you have said STOP, go get help and tell someone.

Understanding Boundaries and Providing Resources

Key Points for Caregivers

Establishing boundaries in relationships can create safe psychological spaces. When individuals with an intellectual disability express their sexuality in inappropriate ways, their behaviour needs to be addressed just as it would with non-disabled individuals. Open demonstrations of sexuality may be linked to mental illnesses and must be reported and discussed with other staff and health professionals. In some instances, the behaviour must be reported to police. Caregivers can model respectful behaviour that shows the difference between private and public actions. This is an important way for individuals with intellectual disability to learn about setting boundaries. Resources are available, such as picture cards and the Circle of Relationships activity.

Differentiating between Challenging Behaviours and Sex Offending Behaviours

People with intellectual disabilities and offending behaviour, including sexual offending, usually access services from both the justice system and disability care services. Staff from different professional groups may not agree on whether the behaviour should be viewed as *challenging* or *sex offending*, Problematic sexual behaviour can be aligned with clinical processes and viewed either way (Doyle, 2004). Although philosophies about challenging behaviour and sex offending behaviour have some characteristics in common, knowing that significant differences exist can be helpful in understanding how to provide consistent and informed support.

Challenging behaviours are viewed as violent and have been defined as "behaviour of such intensity, frequency or duration that the **physical safety of the person or others is placed in serious jeopardy** or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities" (Emerson, 1995, p. 4). Sexually violent behaviour includes actual, attempted, or threatened sexual contact with a person who is non-consenting or unable to give consent (Boer et al., 1997). This includes all sexual contact with children. The behaviour may interfere with the gaining of new skills and learning opportunities, so that the quality of life of others may be impacted as well as the quality of life of the individual with the challenging behaviour. Examples of challenging behaviours include self-injury, self-stimulation, physical and verbal aggression, sexually inappropriate behaviour, and property destruction (Doyle, 2004).

The term *challenging behaviour* has been used as an attempt to avoid further stigmatizing a population of individuals who are already marginalized. It is meant to demonstrate that the behaviour is an adaptive response to other factors or a means of communicating distress to others (as discussed in Chapter 6). Assessment is likely to incorporate indicators of psychiatric disorders. Interventions focus on exploring the environmental, biological, educational, and social factors responsible for the behaviour rather than placing the blame on the individual participating in the behaviour. It is within this way of thinking that clinicians are trying to come to terms with and develop interventions for sexually violent behaviour.

Understanding challenging behaviour requires believing that human behaviour occurs for some reason and within a certain context. Functional analysis is the way clinicians and workers in the intellectual disability field attempt to understand the meaning or communicative intent of the behaviour. The relationship between the behaviour, the preceding events, and the consequences of the behaviour are explored. Treatment processes then look at ways to alter preceding events or consequences in order to change the behaviour and to address the needs the individual is attempting to communicate.

Treatment approaches that view the behaviour as ***sexual offending*** regard the same actions as violent but emphasize protecting the community and preventing the behaviour from reoccurring. Rather than considering the meaning behind the behaviour, this view suggests that individuals must take responsibility for their behaviour and for the consequences of their actions. This way of thinking highlights that there is a risk for both the community and the offending individual if the seriousness of sex offending is underplayed. For example, we cannot hold children or vulnerable disabled adults responsible for triggering an offender`s behaviour, and we cannot just dismiss the damaging consequences of the sex offending behaviour.

There are two important arguments against viewing sex offending behaviour as being simply challenging. First, treatment framed from a sex offending view does not reflect the values inherent in the process of conducting a functional analysis. Second, there is a risk for both the community and the offending individual if the seriousness of sex offending is underplayed. Table 7.2 presents differences between behaviours that are challenging and those that are sex offending (Doyle, 2004).

Table 7.2 Values-based assumptions: Challenging behaviour versus sex offending behaviour

Challenging Behaviour	**Sex Offending Behaviour**
The primary intention of a functional analysis approach to challenging behaviour is to identify the purpose, meaning, and communicative intent of a behaviour in order to provide behavioural support.	Evaluation of intent and motivation is key to understanding offending behaviour. Darke (1990) indicates that committing sexual offences achieves power and control over more vulnerable people through the use of sexual aggression. Sorting out the *how* and identifying the form the behaviour takes and the circumstances under which the behaviour occurs is paramount in order to develop relapse-prevention strategies.
Once the purpose of the individual's behaviour has been determined, behavioural support is given with the primary aim to hold that individual's dignity as a primary concern.	The risky nature of sexual offending behaviour means that the focus needs to be on the behaviour itself rather than the meaning behind the behaviour. The damage to vulnerable victims can have great impact on them for the rest of their lives. While the dignity of the offender is of concern, protecting the community and managing the risk of reoffending behaviour both compete for priority.
In functional analysis, the goal is to understand the purpose of the behaviour in order to teach and develop effective alternatives. The approach is educational and involves the systematic instruction of new adaptive skills.	Assessment of sexual offending behaviour is carried out to prevent and protect the public and not necessarily to understand the purpose of the behaviour for the offender. The educational focus is relapse prevention and addressing contributing factors such as problem solving and decision making, anger management, alcohol and drug abuse prevention, sexuality, and legal issues such as consent. The Association for the Treatment of Sexual Abusers website is a helpful resource (http://www.atsa.com/index.html).
Functional analysis is designed to determine the relationships between environmental conditions and the person's behaviours. The environment has an ongoing reciprocal role in shaping the behaviour and is the focus of developing alternative strategies. Precipitating environmental factors and factors that reinforce or maintain the behaviour are adapted to facilitate the development of more adaptive behaviours. The individual is not blamed.	Removing personal responsibility for offending behaviour is potentially dangerous. In the case of the sexual offender, the environment may be seen as only eliciting the expression of an existing deviant sexual orientation and hence is not a true interaction. Children and vulnerable individuals cannot be held responsible for the offender's behaviour. Many people with intellectual disability who commit sexual offences have limited internal inhibitors and a poor understanding of the legal consequences of their behaviour. It is important to emphasize that the behaviour is wrong, it hurts others, and it has legal and emotional consequences that may affect the quality of life of the offender as well as the victims.

Differentiating between Challenging Behaviours and Sex Offending Behaviours

Key Points for Caregivers

Inappropriate expressions of sexuality are very serious. Whether they are open or violent, they can traumatize victims and leave offenders facing lifelong consequences. Different professional groups do not all agree on the best treatment approaches. Some view sexually violent behaviours that hurt others and interfere with quality of life for others as challenging. Others view these behaviours as sexual offending.

Treatment approaches that view the behaviour as challenging will try to find out why individuals act this way, what the behaviour means, and how it meets an otherwise unmet need. When caregivers are involved, they will admit that the behaviour is unacceptable and hurts others as well as themselves. They will also recognize that the behaviours are occurring for a reason and they will guide individuals toward meeting their needs with more acceptable behaviours.

Treatment approaches that view the behaviour as sexual offending will not focus on what the behaviour means. Here, when caregivers are involved, they will still admit that the behaviour is unacceptable and hurts others as well as themselves. However, they will pay more attention to strategies that prevent the behaviour from reoccurring and to protecting all the people in the community that the individual interacts with.

Although views about treatment approaches are different and each individual is unique, inappropriate expressions of sexuality must all be reported, discussed, and addressed as a team.

Conclusion

In this chapter we have discussed how caregivers can provide sexual education support to their clients through discussion topics, understanding boundaries, and differentiating between challenging behaviours and sex offending behaviours. Individuals with intellectual disabilities are very vulnerable to sexual abuse and victimization. They may not fully understand how to express their sexuality in socially acceptable ways and their consent for sexual activity may not be well informed. Those who are dually diagnosed with a psychiatric disorder are even more vulnerable. Their behaviour may be directly related to a psychiatric disorder and may indicate an escalating mental health crisis.

Caregivers can supplement existing sexual education programs in which clients are or have been involved, through conversations about normal expressions of sexuality such as masturbation, relationships, contraception, sexually transmitted diseases, and safe sex practices. Individuals with intellectual disabilities may be parents. For these parents to be supported toward retaining custody of their children and enjoying their family life, they need most to be surrounded by a network of caring, helpful people.

Understanding boundaries, or the limits we create within relationships to feel psychologically safe, is critically important. Inappropriate expressions of sexuality such as masturbation in public, genital exposure, inappropriate sexual touching, and embracing others too closely should not be tolerated. When non-disabled individuals demonstrate this behaviour, it is viewed as inappropriate and often reported to police. Individuals with disabilities are just as accountable for their behaviour. Caregivers and others in their environment should not be made to feel uncomfortable or psychologically unsafe because of an individual's behaviour. The behaviour should not be ignored. It should be discussed among agency staff, recorded, and reported according to agency policy. Caregivers can model how to set boundaries by requiring acceptable personal space during their interactions with clients.

Any inappropriate expression of sexuality must be taken seriously. People who witness, who are victimized, or who are assaulted as a consequence of these behaviours can be left devastated. Perpetrators are usually penalized. Although professionals do not always agree about whether the behaviour should be viewed as challenging or as sex offending, there is a clear consensus that the behaviour is hurtful, unacceptable, and must stop. Children and other adults must be protected and individuals must find strategies to prevent the behaviour from reoccurring.

Finally, adults with intellectual disabilities can embrace their sexuality every bit as fully as everyone else in society. Knowing this, seeking ways to ensure these adults have the knowledge they need can become a priority.

Increasing clients' expressions of their sexuality in healthy ways will allow others to see their capabilities and personalities as people we value and want to come to know.

Chapter Audio for Print

This chapter contains a number of short audio clips. If you are reading this in print, you can access the audio clips in this chapter by scanning this QR code with your mobile device. Alternatively, you can visit the book website at opentextbc.ca/caregivers and listen to all the audio clips.

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PART 1

Audio Compendium

CHAPTER 1: SUPPORT WORK: THE FUNDAMENTALS

Guiding Principles for Support Work

Key Points for Caregivers

Guiding principles for support work state that people with disabilities have rights that relate to

1. citizenship, through freedom from discrimination
2. individual control, through involvement in decisions related to their lives
3. equality and human rights, through the benefits and protection of the law
4. universal design, through barrier-free environments.

"To deny people their human rights is to challenge their very humanity."

— Nelson Mandela

Historical Struggles

Key Points for Caregivers

In the past, people with disabilities were rejected, laughed at, and even put to death. Today, disability services emphasize the importance of including people with disabilities in communities. *Social role valorization* encourages communities to provide normal living, education, and employment opportunities whenever possible. *Rosa's Law* requires that the term *mental retardation* is replaced with the term *intellectual disability*.

Competencies Expected of Support Workers

Key Points for Caregivers

Caregivers who support individuals with disabilities, particularly caregivers who are employed as direct support workers, are expected to be competent and able to work with others to

1. assess the strengths and needs of clients
2. plan and provide services
3. link to resources
4. advocate
5. record information and write reports
6. demonstrate professional and ethical behaviour
7. tailor support requirements in relation to unique requirements of clients

CHAPTER 2: WHAT'S IN A NAME?

The Impact of Names Beyond the Hurt Feelings: Implications for Service and Support

… Language to AVOID

Key Points for Caregivers

1. Avoid describing persons with intellectual disability as all the same. For example, avoid using the word *the*, as in *the intellectually disabled*, when talking about individuals with intellectual disability. This form of description treats persons with disability as objects and interferes with recognizing each person’s uniqueness.

2. Avoid referring to individuals as particularly remarkable or interesting because they are persons with intellectual disabilities. Language that sets individuals or groups apart as somehow *special* or unusual because of their disability actually reduces their value as human beings. This includes praising someone as *brave* or *courageous*, simply because that person has an impairment.

3. Avoid using language that expresses pity for a person with disability or for their family. For example, avoid comments such as “It’s just so unfair (or “What a shame” or “What a pity” or “How awful”) that your son has to live with such a disability.”

4. Avoid polite terms or language that is vague and confusing. Though some terms sound sensitive, such as *differently abled* or *developmentally challenged*, those terms only indicate that a disability exists. They do not actually identify the disability

5. Avoid using language that labels a person with intellectual disability as someone who *suffers from*, is a *victim of*, or is *afflicted with* the disability. These descriptions give negative suggestions about the person with the disability.

6. Avoid using language that describes persons with intellectual disabilities as having lower status. For example, by describing persons without disabilities as *normal*, individuals with disabilities are suggested to be *abnormal*. This can suggest that persons with disability are not good enough to belong to the preferred group, *normal.*

The Impact of Names Beyond the Hurt Feelings: Implications for Service and Support

… Language To USE

Key Points for Caregivers

1. Use language that is respectful, caring, and kind, and that communicates that the person is valued.
2. Use language that is appropriate to age and culture. For example, when meeting an older adult, a common custom may be to use a greeting such as: “I am pleased to meet you Mr. Dodge. May I call you Henry?” rather than presuming that Mr. Dodge can be called Henry simply because he has intellectual disability.
3. Use language that is preferred by the person living with the disability. For example, members of the People First self-advocacy organization in Great Britain prefer to say that they experience “learning difficulties” instead of saying that they have intellectual disability, or a learning disability.
4. Use the person’s name and discuss issues in the same way that you would discuss issues when talking with or talking about someone who does not live with intellectual disability.
5. Treat each person as a person first, and with the understanding that using diagnostic labels is required only rarely and only in highly specific situations.

CHAPTER 3: AN OVERVIEW OF MENTAL ILLNESS

Indicators Associated with Disorders of Thinking: Schizophrenia

Key Points for Caregivers

1. With schizophrenia, all those who care for verbal clients must try to **know the content of any hallucination or delusion** their client is experiencing or has experienced. A typical hallucination might involve a deep, loud commanding male voice repeatedly telling a client that he or she is “worthless and must die.” Caregivers are expected to pose a clear question, such as “Are you hearing voices right now?” when clients are talking to themselves.

2. Caregivers of non-verbal clients must try to **determine if hallucinations or delusions are occurring**. Indicators of hallucinations include

   a. Staring to the side and nodding and making hand motions as though listening to a conversation others do not hear.

   b. Physically attacking an unseen other person.

   c. Staring with an angry or frightened expression at strangers or well-liked companions, in a situation that does not require those emotions.

   d. Covering the eyes or ears as if to protect oneself, when threats are not present.

   e. Frowning as though something smelled or tasted foul.

   f. Dressing in protective ways such as wrapping on extra scarves or blankets when the weather does not require it.

3. The nature of schizophrenia prevents the client from understanding that the voices or other hallucinations or delusions are not real. The only treatment that is effective in decreasing the thought changes in schizophrenia is antipsychotic medication. Without medication, trying to orient clients to reality can bring on profound anxiety and even aggressive actions. Caregivers must **know what psychiatric medications have been prescribed**.

4. The major side effects of psychiatric medication are a further challenge to treating schizophrenia. Hallucinations and delusions often include the belief that antipsychotic medication is *poison*. In response to this belief, psychotic clients frequently pretend to swallow pills, or *cheek*. Given this unchangeable reluctance to swallowing pills, clients often receive long-acting antipsychotic medications intra-muscu-

larly during monthly clinic visits. However, caregivers must **always watch clients swallow their psychiatric medications**.

Indicators Associated with Disorders of Thinking: Psychosis

Key Points for Caregivers

1. With psychosis, determine whether clients know that **fantasy conversations** are not real.
2. Rule out **dehydration**, particularly in clients who are elderly.
3. Ask whether the client has been having seizures or has a **seizure disorder**.
4. Note whether a **new medication** or new medical condition is present.
5. Document any **street drug use,** as many drugs induce psychotic-like behaviour.

Indicators Associated with Disorders of Thinking: Dementia

Key Points for Caregivers

1. **Keep records of changes in behaviour and loss of previous abilities.** This is especially important to health care workers diagnosing dementia. Therefore, maintaining clear records of how clients function throughout their adult life is useful. These records can be formal medical charts obtained from physicians, or they can be informal records obtained from family members or clients themselves. Scrapbooks, photo albums, video home movies, and audio recordings will illustrate how clients spoke, moved, and responded when they were well and healthy. Comparing a previous picture, audio, or video with a current cell phone capture of a client can clarify changes that are happening.
2. **Record specific examples of physical weakening, particularly in speaking and walking.** For example, identify how a client's gait or how they walk is changing. Keep a record of any falls, stumbles, or times when clients seem to lose their balance.
3. **Prepare for and seek medical help immediately if seizures occur.** A seizure in someone previously unaffected, and that is not part of a medical condition, can indicate dementia.
4. **Understand and identify how often *confabulation answers* are occurring. Confabulation means *making up* answers without intending to lie.** Knowing that clients with dementia are not lying or making things up on purpose can help caregivers understand that this behaviour is part of a psychiatric disorder and not acting-out behaviour.
5. **Understand and identify how often *sundowning* is occurring. Sundowning means increased**

agitation in the evening. Clients may seem to be expressing anger by behaviours such as screaming and yelling, but it is important to understand that this behaviour is likely a response to an intense and constant inner fear that clients are unable to escape.

6. **Create and communicate supports that help memory lapses.** People with dementia are forgetful, get lost, and can have difficulty recognizing friends, family, and staff. Whenever possible, create cues to help with memory loss, such as calendars of events, photo collections, or scrapbooks. Ensure that these cues are consistent and that as many people as possible in the client's life know about them.

Indicators Associated with Disorders of Mood: Vegetative Shift

Key Points for Caregivers

Vegetative shift is a term used by mental health professionals to describe problems associated with depressive disorders. A vegetative shift occurs when vegetative signs shift or change. Critical vegetative signs include affect, energy, pleasure, appetite, sleep, and thoughts of suicide. A memory aid for indicators of vegetative shift is "A E P A S S."

Use the "A E P A S S" (Affect, Energy, Pleasure, Appetite, Sleep, Suicide) memory aid to document a shift in vegetative signs.

- **"A" – an Affect of sadness and poor concentration.** Identify sad facial, postural, and emotional responses that last for weeks at a time and that do not seem to fit the context. Sadness in clients may or may not be a response to something that has happened. Clients may show their depression through crying, becoming withdrawn and non-responsive, or becoming agitated and verbally and physically aggressive.
- **"E" – Energy loss and fatigue.** Write down the number of times clients are refusing to leave their beds, take care of activities of daily living such as bathing and dressing, and attend work or leisure activities. Include times when either constipation or incontinence occurs in relation to lacking the energy to go to the bathroom. Include the number of hours clients spend sitting or lying down for long periods of time just watching TV or doing nothing.
- **"P" – Pleasure or interest.** Notice whether clients are no longer taking pleasure in activities they once enjoyed. Notice also when clients with a bipolar disorder are cycling into a manic or hyperactive state, when they may carry out pleasurable activities impulsively. In particular, monitor reckless behaviour in spending money and sexual activity.
- **"A" – Appetite changes.** Appetite can increase or decrease in depressive disorders. Carefully record client weight and identify any gains or losses. Tantrums at meals, and stealing or hoarding food for constant nibbling, can reflect a need to soothe the emotional distress of depression. In contrast, refusing to take time to eat can reflect the hyperactivity associated with a manic state.
- **"S" – Sleep disturbances.** Keep a record of the number of hours clients sleep each night, including the time they go to bed, the number of times they get up in the night, and the time they wake up. Dif-

ficulty falling asleep can be an indicator of anxiety. Waking up early can be an indicator of depression. Sleeping in late can be a response to dysthymia, where people feel sad in the morning but then feel better as the day progresses. Remaining in bed and sleeping or dozing for long periods of time during both night and day can be a way of withdrawing that is often associated with depression. In contrast, going to bed late, getting up frequently in the night, and getting out of bed early can indicate a pattern of hyperactivity associated with a manic state.

- **"S" – Suicidal thinking.** Ask verbal clients if they have thought about taking their own life, if they have a plan to do so, and what (if anything) stops them. Assess if clients seem to speak often about death when such discussions are out of context. Probe whether the thinking behind self-harming behaviour is related to an intent to commit suicide. **Important: Remove any objects that could be used for self-harm.**

Indicators Associated with Disorders of Mood: Anxiety, Post-traumatic Stress Disorder (PTSD)

Key Points for Caregivers

1. Monitor sleeping and **identify whether nightmares are occurring**. When possible, identify what the nightmares are about.
2. **Record situations when clients seem fearful**, particularly when there does not seem to be anything or anyone around who could hurt them. Notice if clients avoid certain situations or individuals by verbal and non-verbal resistance and behaviours.
3. Provide records of known traumatic events to caregivers and family members. Exchange information about these events to **distinguish whether they are new traumas or flashbacks**.

Indicators Associated with Disorders of Mood: Anxiety, Obsessive-compulsive Disorder (OCD)

Key Points for Caregivers

1. **Delay rather than interrupt ritualistic behaviours.** Expect that clients may respond with aggression when re-directed away from their repetitive behaviours. When caregivers view the behaviours through the eyes of clients, caregivers can acknowledge a client's belief that these behaviours are the only possible relief from unbearable anxiety.

2. **Prepare for and seek medical help immediately if seizures occur**, particularly if clients have or have the potential for seizure disorders and are taking the antidepressant medication clomipramine (also called Anafranil).
3. **Make comfort measures available when ritualistic behaviours result in physical symptoms.** For example, hand lotion for excessive hand washing, and padding or helmets for head banging.

Indicators Associated with Disorders of Behaviour: Borderline Personality Disorder

Key Points for Caregivers

1. Gather as much information as possible about clients' **patterns** of over-reacting and behaviour that is harmful to self or others. Identify if the patterns began occurring at a young age and whether any elements of the behaviour have changed and improved over time and with support.
2. With borderline personality disorder, **consistent communication among caregivers** is critically important. Divisions among caregivers can occur if clients *split* or view individuals around them only as all good or all bad.

CHAPTER 4: COMMON PHYSICAL CONCERNS

Health Status

Key Points for Caregivers

Those who support and care for persons with intellectual disability can get clear signals from findings of research with Special Olympic athletes.

1. Arrange routine vision and hearing examinations, particularly for age-related deterioration. Adults with Down syndrome are particularly likely to have vision and hearing problems. Those over the age of thirty are at increased risk for early development of cataracts, refractive errors such as near- and far-sightedness, and degeneration of the cornea.
2. Encourage healthy dietary habits and promote or provide regular daily dental hygiene. Schedule routine dental appointments for cleaning, examinations, and maintenance of oral health. Individuals with intellectual disability are much more likely than individuals without disability to report that they have not had their teeth cleaned by a dental hygienist within five years, or that they have never had their teeth cleaned by a dental hygienist.
3. Promote or provide proper foot care, ensuring that cleanliness is maintained, nails are correctly cut, and clean socks and properly fitting shoes are worn. It's been said that to determine how well a person with disability or dependency needs is being cared for, check the condition of his or her teeth and toenails. Although this form of assessment is far too simplistic, it does provide a telling measure.
4. Provide well-balanced meals and regular weight-bearing exercise such as walking to promote overall health and bone maintenance. Individuals with Down syndrome as well as underweight or small-boned individuals are more at risk of bone loss and osteoporosis. Also at risk are individuals who experience delayed puberty or early menopause, which can be part of some conditions linked with intellectual disability.

Factors Affecting Health Status

Key Points for Caregivers

People with intellectual disability have the right to be as healthy as anyone else. They also have the right to the same health care access and treatment as others within the general population. Examples of legislation that protects the equality rights of all persons with disability are section 15 of the 1982 Canadian Charter of Rights and Freedoms, the 1990 Americans with Disabilities Act, and Britain's 1995 Disability Discrimination Act. In addition, the 2006 United Nations Convention on the Rights of Persons with Disabilities is a declaration of commitment to equality rights that has now been ratified by 143 countries.

Common Health Challenges: Constipation

Key Points for Caregivers

1. Prepare or promote the preparation of well-balanced meals that include adequate sources of fibre such as fruits, vegetables, and whole grain breads.
2. Encourage adequate fluid intake. Eight glasses of water or other fluids each day can be considered adequate, unless an individual has fluid intake restrictions or other requirements. Caffeine-containing drinks have a dehydrating effect and milk or dairy-based drinks may be constipating for some people.
3. Promote or provide regular daily exercise. For individuals in wheelchairs, occasional side-to-side movement, if possible, or exercise while seated in the chair may be helpful. A physiotherapist may be able to recommend exercises and activities.
4. Encourage supported individuals to move their bowels when they feel the urge.

Medical assistance should be sought

1. if constipation is experienced for the first time or there has been a change in bowel routine
2. if constipation does not respond to natural remedies such as increased dietary fibre or fluid intake, or to replacing sedentary activity with regular exercise such as walking or swimming
3. if blood is evident in stool or during bowel movements, or rectally at any other time
4. if unplanned weight loss occurs
5. if pain occurs with bowel movements, or abdominal pain or cramps occur
6. if nausea or vomiting occur
7. if constipation lasts for more than two weeks.

Common Health Challenges: Epilepsy

Key Points for Caregivers

1. Be conscious of situations and conditions that are likely to trigger seizures for supported individuals. Avoid or reduce exposure to triggers whenever possible.
2. Provide appropriate assistance to the individual if a seizure does occur.
3. After a seizure, record the conditions under which the seizure occurred, along with a description of the seizure activity. Describe how long the seizure lasted and emergency measures if needed. Describe any events that accompanied the seizure, such as loss of bladder control or injury. Describe the nature of the recovery after the seizure.

Common Health Challenges: Mistreatment

Key Points for Caregivers

The foundation to providing appropriate support is respect for the right of individuals with intellectual disability to make informed choices and decisions about their own lives. *Informed* choices and decisions mean that people make their decisions based on a full and adequate understanding of all available options and their possible consequences. For supported persons with intellectual disability, it also means that they are able to discuss choices with people who are important to the decision and who genuinely have the best interests of the supported person in mind. When more severe disability exists, others must make decisions based on how they understand the supported person’s wishes and values, still in the genuine best interests of that person.

Health Promotion

Key Points for Caregivers

Men and women with intellectual disability often lack the skill and opportunities to independently practice healthy living. Support providers and health care professionals are important to maintaining and improving health of people with intellectual disability through healthy living practices. This means that it is important for support providers and health care professionals to locate or develop best practice health promotion programs and then apply those programs. This gives persons with intellectual disability the same opportunities to live healthy lives as other citizens.

CHAPTER 5: WHEN THE PROBLEM IS PAIN

The Hierarchy of Pain Assessment Techniques

Key Points for Caregivers

Hierarchy of Pain Assessment

1. Obtain self-report
2. Search for potential causes
3. Observe behaviours
4. Obtain proxy reporting
5. Attempt trial of pain medication

CHAPTER 6: BEHAVIOUR THAT HURTS

Overview of Applied Behavioural Analysis

Key Points for Caregivers

People may hurt themselves (called self-injury) or other people (called aggression). Self-injury or aggression may occur because of pain, a health-related disorder, stress, as a symptom of a psychiatric disorder, or because a person lacks social skills. Medications may even make the problem worse. These possibilities must all be investigated. Challenging behaviour that starts for one reason may continue even when that reason is no longer there. Behavioural analysis looks at what needs are served by a behaviour and then finds other ways that people can meet those needs.

Functional Behavioural Analysis

Key Points for Caregivers

Functional behaviour analysis helps us understand why people continue injuring themselves or being aggressive. Three common reasons for any behaviour are that it:

1. provides an ***escape*** from something a person does not like
2. provides ***access*** to something a person does like
3. provides stimulation that a person can create when they are ***alone***.

When people need to escape from an activity that is difficult or unpleasant, providing a break may help. When they need access to something they value, such as favourite people, food, or activities, providing this access before challenging behaviour begins may prevent the challenging behaviour from occurring. When people are alone and need stimulation, they can be given alternatives through opportunities for them to see, hear, smell, touch, and taste.

Topography of Behaviour

Key Points for Caregivers

Challenging behaviours must be described and reported in detail so that others have a clear picture of what people are actually doing. Topography of behaviour, like topography of a geographic area illustrated in a map, describes only what is there and what we see. Topographies of behaviour do not judge value or include expectations.

Strategies to Help Decrease Self-Injurious and Aggressive Behaviour

Key Points for Caregivers

Strategies to help decrease self-injurious and aggressive behaviours provide individuals with alternative ways to meet their needs.

1. When people need to escape difficult situations, strategies can prevent escape, can offer instruction to make the situation less difficult, or can offer an alternative way to escape.

2. When people want access to stimulation they like, such as food, activities, or attention from people, strategies can make these people and things available. Strategies can include

    a. card reading or saying “Help please” or “Break please” as an alternative to aggressive or self-injurious behaviour

    b. presenting fewer or less difficult tasks for the individual to complete

    c. breaking down larger or complex tasks into smaller steps

    d. providing help and prompts to the individual at regular and ongoing points of time, only reducing help when the individual shows that he or she has mastered the skill independently

3. When people want stimulation for their senses when they are alone, strategies can offer comparable ways to experience the sensations and feelings. An example of a strategy is substituting appropriate food treats to provide alternate sensations experienced during hand mouthing.

    a. regular scheduled praise from a caregiver, such as ‘Good job not …’ when challenging behaviour does not occur within a specified period of time

    b. providing preferred items for the individual to interact with instead of engaging in challenging behaviour.

CHAPTER 7: SEXUALITY

Discussion Topics for Sexual Education Support

Key Points for Caregivers

Sexual health is often overlooked in individuals with intellectual disabilities. They are very vulnerable to sexual abuse and may not understand what consenting to sexual activity means. They may not know how to express their sexuality. Sex education programs often include important discussions of normal expressions of sexuality such as masturbation, relationships, contraception, sexually transmitted diseases, and safe sex practices. These kinds of topics must also be part of the everyday conversations that take place between intellectually disabled individuals and the people in their lives. When individuals with intellectual disabilities are parents, they need a network of people around them and opportunities to learn about children's development and showing appropriate affection to children.

Understanding Boundaries and Providing Resources

Key Points for Caregivers

Establishing boundaries in relationships can create safe psychological spaces. When individuals with an intellectual disability express their sexuality in inappropriate ways, their behaviour needs to be addressed just as it would be with non-disabled individuals. Open demonstrations of sexuality may be linked to mental illnesses and must be reported and discussed with other staff and health professionals. In some instances, the behaviour must be reported to police. Caregivers can model respectful behaviour that shows the difference between private and public actions. This is an important way for individuals with intellectual disability to learn about setting boundaries. Resources are available, such as picture cards and the Circle of Relationships activity.

Differentiating Between Challenging Behaviours and Sex Offending Behaviours

Key Points for Caregivers

Inappropriate expressions of sexuality are very serious. Whether they are open or violent, they can traumatize victims and leave offenders facing lifelong consequences. Different professional groups do not all agree on the best treatment approaches. Some view sexually violent behaviours that hurt others and interfere with quality of life for others as *challenging*. Others view these behaviours as *sexual offending*. Treatment approaches that view the behaviour as *challenging* will try to find out why individuals act this way, what the behaviour means, and how it meets an otherwise unmet need. When caregivers are involved, they will admit that the behaviour is unacceptable and hurts others as well as themselves. They will also recognize that the behaviour is occurring for a reason and they will guide individuals toward meeting their needs with more acceptable behaviours.

Treatment approaches that view the behaviour as *sexual offending* will not focus on what the behaviour means. Here, when caregivers are involved, they will still admit that the behaviour is unacceptable and hurts others as well as themselves. However, they will pay more attention to strategies that prevent the behaviour from re-occurring and to protecting all the people in the community that the individual interacts with.

Although views about treatment approaches are different and each individual is unique, inappropriate expressions of sexuality must all be reported, discussed, and addressed as a team.

Versioning History

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Version	Date	Change	Details
1.1	February 17, 2015	Book added to the BC Open Textbook Collection.	
1.2	March 17, 2017	Replaced an incorrect citation.	Chapter 3: In the first sentence in the section on dementia, the author had cited Mayo Clinic in text. This in-text citation was replaced with Alzheimer's Society, and the full citation at the end of the chapter was updated as well.