1.2: What’s in a Name?

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 Although Edgerton’s terminology is now out of date, concern about the effects of stigma on the lives of people with intellectual impairment remains.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.”
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.

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**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.

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**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

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<tr>
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<th>IQ Above 70–75</th>
<th>IQ Below 70–75</th>
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<tbody>
<tr>
<td>No significant adaptive behaviour limitations</td>
<td>NO intellectual disability</td>
<td>NO intellectual disability</td>
</tr>
<tr>
<td>Significant adaptive behaviour limitations</td>
<td>NO intellectual disability</td>
<td>YES intellectual disability *Plus: occurs before age 18</td>
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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.
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.

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

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References


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