chapter 20

Disability Studies in Inclusive Education

The nature of intellectual disability and its impact on learning

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Chapter learning outcomes

After completing this chapter, you will be able to:

- ✓ Describe the nature of intellectual disability and its causes.
- ✓ Examine the effects of intellectual disabilities on children in the classroom.
- ✓ Explore the barriers experienced by learners and the impact this has on caregivers and parents, with specific relation to family-professional partnerships.
- ✓ Reflect on the experiences of children with severe to profound intellectual disabilities (SPID) and their families in an empathetic way.
- ✓ Explore the perspectives of parents and caregivers in the education of learners who have SPID.

Preparatory activities

WATCH: TEDI 4 week 1 – Understanding the impact of intellectual disability ○

Creator: Judith McKenzie
Date: 2019
Duration: 11 minutes

READ: Family-professional partnerships: Why they are needed for inclusive education to work in South Africa ○

Author: Teacher Empowerment for Disability Inclusion (TEDI)
Estimated reading time: 30 minutes
File size: 459 KB

Introduction

In this chapter, we examine intellectual disability. While there are various levels of intellectual disabilities, we focus on SPID. We recognise that learners with SPID are the most neglected of children in the education system. Despite the belief that these children are ineducable, they are able to learn when they are given the right opportunities to do so. In this chapter, we consider the human rights of learners with intellectual disabilities and the ways in which their families are affected. We also briefly consider the impact of intellectual disability on learning in children with less severe intellectual disability.

The American Association on Intellectual and Developmental Disabilities (AAIDD) cautions against defining persons only in terms of deficit and states that every person, no matter what their disability, has strengths that can be built upon by providing the right kind of support. This chapter examines possible support approaches.

GLOSSARY: Intellectual disability

Intellectual disability is “a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development” (**Department of Health, 2001, p. 14**).

When considering ways to support a learner with an intellectual disability, we need to think of the levels of support available around the child. This means taking the community and environment into account, including factors related to linguistic diversity and cultural differences in the way people communicate, move and behave.

As a starting point, we will briefly examine the experiences of persons with intellectual disabilities in the past and how things have changed over the years.

Historical perspective

Historically, persons with intellectual disabilities have been one of the most stigmatised and marginalised groups in society, which was reflected in the negative terms used to refer to people, such as “retarded”, “moron”, “feeble-minded”, “idiot”, “demented”, “imbecile” and “mongoloid” (**Conrad, 2020**).

In the Middle Ages, persons with SPID were called by these names and treated badly, as the disabilities were thought to be caused by demons. Others believed that persons with intellectually disabilities were spiritually possessed. During this period, persons with intellectual disabilities were ostracised (**Conrad, 2020**).

In the 18th and 19th centuries, there was a lot of progress and development in terms of educating persons with intellectual disabilities. Alongside this, there was also a move towards removing persons with intellectual disabilities from their families and confining them to mental institutions. This was not just to “protect” persons with intellectual disabilities, but also to protect society at large by locking away persons who were seen to be different and therefore dangerous.

Although we have more positive attitudes towards people with intellectual disabilities today due to scientific research and policy changes that address human rights and discourage the use of hurtful and derogatory names, persons with intellectual disabilities continue to be stigmatised, suffering exclusion from all social activities. There are also still people who perceive that the only solution to this so-called “problem” is through spiritual healing by prophets or fetish priests. Despite this way of thinking, more people are being informed and educated, which is resulting in a positive change in their way of thinking about and interacting with people with intellectual disabilities (**Conrad, 2020**).

As a way to start addressing these experiences, we need to understand the nature of intellectual disability and the barriers prohibiting learners with these disabilities from participating in society, specifically as relates to accessing curriculum and education.

GLOSSARY: Barriers to learning

Barriers to learning refers to the “difficulties that arise within the education system as a whole, the learning site and/or within the learner him/herself which prevent access to learning and development” (**Department of Basic Education, 2014, p. vii**). “Barriers to learning arise from the different aspects of the curriculum such as the content, the language, classroom organisation, teaching methodologies, pace of teaching and time available to complete the curriculum, teaching and learning support materials and assessment” (**Department of Education, 2001, p. 19**).

GLOSSARY: Curriculum

Curriculum consists of “the courses, lessons, and learning activities students participate in, as well as the knowledge and skills educators intentionally teach to students, the hidden curriculum consists of the unspoken or implicit academic, social, and cultural messages that are communicated to students while they are in school” (**Great Schools Partnership, 2015, para. 1**).

What is intellectual disability?

Intellectual disability affects the development of a child, starting before the age of 18 years and continuing throughout life. It affects the brain and can also affect physical abilities.

There are many causes of intellectual disability. The most common are:

- Causes before birth (prenatal).
- Causes during birth (perinatal).
- Causes during childhood (postnatal).
- Biomedical and environmental causes.

Intellectual disability results in children developing and learning slower than typical children in their age in two main areas: intellectual functioning and adaptive functioning.

Intellectual functioning is the ability to acquire and apply knowledge and skills by using reasoning, problem solving, abstract thinking, judgment, academic learning and learning from experience. Adaptive functioning is defined as the ability to adapt to the needs of everyday living. This requires certain skills such as conceptual, social and practical skills. With ongoing support, the person with intellectual disability can function in more activities of daily life (**Adnams, 2016**).

Intellectual functioning is often assessed with standardised IQ tests in conjunction with other tools. These tests provide standard scores, which can be useful but should be treated with caution, as they are often inappropriate and provide a limited sample of behaviour. Adaptive functioning assessments measure the conceptual, social and practical skills needed to cope with everyday living. Generally, there are four categories of intellectual disability: mild, moderate, severe and profound (**Adnams, 2016**).

It is important to differentiate between intellectual disabilities and learning disabilities. Intellectual disability refers to when somebody has a global developmental disorder, whereas a learning disability refers to when a person has difficulty learning in a specific academic area (**American Psychiatric Association [APA], 2021**). Table 1 provides examples of characteristics associated with each of these kinds of disability.

Table 1: Examples of characteristics associated with intellectual and learning disabilities

Intellectual disability (e.g. Down syndrome, autism spectrum disorder, foetal alcohol syndrome)	Learning disability (e.g. dyslexia, dysgraphia, dyscalculia)
Significant below-average intelligence	Average or above average intelligence
Affects general intellectual functioning	Does not affect general intellectual functioning
Impaired adaptive functioning	Impaired abilities: listening, reading, writing, speaking, calculations

The Western Cape Forum for Intellectual Disability pamphlet on understanding intellectual disability provides further information on intellectual disability, its causes and how to find the necessary resources for assistance.

READ: Understanding intellectual disability ○

Author: Western Cape Forum for Intellectual Disability
Estimated reading time: 30 minutes
File size: 431 KB

It is often believed that people with intellectual disabilities are all similar, but there are vast differences across disabilities that have an impact upon one's ability to learn and the support required. The Diagnostic and Statistical Manual of Mental Disorders, currently in its fifth edition (DSM-5-TR) is a taxonomic and diagnostic tool published by the American Psychiatric Association and used by mental health professionals. The DSM-5-TR (**APA, 2022**) provides a functional description of different levels of intellectual disability severity which looks at function in terms of the conceptual, social and practical domains. This is very helpful when it comes to understanding that the level of intellectual disability severity is best understood by looking at the function of a person rather than by IQ scores. So, rather than focusing on the IQ score, we are able to determine what the learner can and cannot do – and, more importantly, what we can do to support the learner.

When considering the type of support that the learner might require, it is not only important to consider the severity of the condition, but the co-occurring and associated conditions as well. Table 2 provides examples of different types of conditions associated with intellectual disability. Followed by the different levels of intellectual disabilities which clearly explains the impact on the learning and development of a learner with intellectual disability.

Co-occurring conditions are defined as medical or psychiatric conditions which occur alongside a particular condition. For example, for children with autism spectrum disorders social anxiety is one of the most common co-occurring anxiety disorders (**APA, 2022**). Associated conditions are defined as aspects or features of the primary condition; that is, they are expected elements of its pathology, although their expression may be variable. Examples of commonly associated conditions are providing in the table below (**APA, 2022**).

Table 2: Examples of co-occurring and associated conditions experienced by persons with intellectual disabilities

Co-occurring conditions	Associated conditions
Epilepsy	Down syndrome
Autism spectrum disorder	Foetal alcohol syndrome
Cerebral palsy	William syndrome
Spina bifida	Fragile X syndrome
Attention deficit hyperactivity disorder	Prader Willi syndrome
Hydrocephalus/microcephaly	Angelman syndrome

The impact of intellectual disability on learners

There are four levels of intellectual disability: (1) mild, (2) moderate, (3) severe and (4) profound. These levels each have implications for conceptual, social and practical functioning. Although we are largely focused on severe to profound intellectual disabilities, understanding the other levels provides clearer understanding of all degrees of intellectual disability. These levels of intellectual disability and how they impact learning for learners with intellectual disability are discussed below.

The following sub-sections, which describe characteristics related to the conceptual, social and practical functioning of learners with mild, moderate, severe and profound intellectual disabilities, are drawn from a presentation by Taryn du Toit from Cape Mental Health.

Mild intellectual disability

The following characteristics related to conceptual, social and practical functioning are typical of persons with mild intellectual disability.

Conceptual functioning

In very young children there might be no obvious problems present, but when it comes to school-age children, there are difficulties in learning academic skills involving reading, writing, maths, time or money and these learners might need curriculum adaptation in schools.

In adults, abstract thinking, short-term memory and functional use of academic skills are reduced. This results in a somewhat concrete (as opposed to abstract) way of thinking.

Social functioning

Communication, conversation and language are more concrete or immature than expected for age.

There may be difficulties in regulating emotion and behaving in an age-appropriate fashion. These difficulties are noticed by peers in social situations.

There is also limited understanding of risk in social situations as social judgement is immature for age; and the person is at risk of being manipulated by others (gullibility).

Practical functioning

The individual may function age-appropriately in personal care, but may still need some support with complex daily living tasks in comparison to peers.

As an adult, support would include shopping, transportation, home and childcare, nutritious food preparation, banking and money management. Recreational skills are the same as their peers but judgement around well-being and organising recreation time requires support. Employment is likely to be found in jobs that do not emphasise conceptual skills.

Individuals generally need support to make healthcare and legal decisions, and to learn to perform a skilled vocation competently.

Moderate intellectual disability

The following characteristics related to conceptual, social and practical functioning are typical of persons with moderate intellectual disability.

Conceptual functioning

It is clear from the start that the individual's conceptual skills are well behind those of their peers.

For pre-schoolers, language and pre-academic skills develop slowly.

For school-age children, progress in reading, writing, maths and understanding of time and money develop more slowly across the school years and the level achieved is limited compared to their peers.

As adults, academic skill development is typically at primary school level. Support is required for academic skills in work and personal life. Ongoing support for conceptual tasks will be required across their lifespan.

Social functioning

The individual relies more on the spoken word than the written word for communication.

They are able to have close relationships and have romantic partners. However, they may not perceive or interpret social cues accurately. Social judgement and decision-making abilities are limited and caregivers must assist with life decisions.

Practical functioning

The individual can do most activities of daily living if the time is taken to teach them to become independent; although reminders may be needed.

Persons can do household chores, although an extended period of teaching is needed and ongoing support will be needed for adult-level performance.

Independent employment in jobs that require limited conceptual and communication skills can be achieved, but considerable support from co-workers, supervisors and others will be needed.

Recreational skills usually require additional support and learning opportunities over an extended period of time. Challenging behaviour is present in a significant minority and causes social problems.

Severe intellectual disability

The following characteristics related to conceptual, social and practical functioning are typical of persons with severe intellectual disability.

Conceptual functioning

The individual generally has little understanding of written language or of concepts involving numbers, quantity, time and money. Caregivers need to provide extensive support for problem solving throughout the individual's life.

Social functioning

Spoken language is quite limited in terms of vocabulary and grammar. Speech may be single words or phrases and may be supplemented through augmentative means, such as gesture, signs or pictures.

Speech and communication are focused on the "here' and now" within everyday events. Relationships with family members and familiar others are a source of pleasure and help.

Practical functioning

The individual requires support for all activities of daily living, including meals, dressing, bathing and toileting. The individual requires supervision at all times. The individual cannot make responsible decisions regarding well-being of the self or others without some support.

In adulthood, participation in tasks at home, recreation and work requires ongoing support and assistance. Learning new skills always involves long-term teaching and ongoing support. Some individuals at this level might show behaviours that are difficult to handle.

Profound intellectual disability

The following characteristics related to conceptual, social and practical functioning are typical of persons with profound intellectual disability.

Conceptual functioning

The individual has very limited conceptual skills and is best able to deal with concrete objects rather than symbols such as pictures or words and may use objects for specific purposes for self-care, work and recreation.

They can learn skills such as matching and sorting based on physical characteristics. However, there is a high likelihood of additional motor or sensory impairments which make learning difficult.

Social functioning

The individual struggles with symbolic communication in speech or gesture. They may understand some simple instructions or gestures and express their desires and emotions largely through non-verbal, non-symbolic communication. The individual enjoys relationships with well-known family members, caregivers and familiar others, and initiates and responds to social interaction through gestural and emotional cues. Additional sensory and physical impairments limit the amount and quality of social interaction and extensive support might be needed to ensure that this happens.

Practical functioning

The individual is dependent on others for all aspects of daily physical care, health and safety. They may or may not be able to participate in certain day-to-day activities. When the person does not have physical impairments, they can assist with simple chores around the home. With support, it is possible to engage individuals in vocational tasks that depend on simple actions with objects, such as sticking on a label. Recreational activities may involve enjoyment in listening to music, watching movies, going out for walks or participating in water activities; all of which need to take place with the support of others.

Additional physical and sensory impairments often limit the extent to which the individual can participate in activities and without support they might spend a lot of time just watching others. These individuals might show difficult and disruptive behaviour in some cases.

It is important to note that these levels of severity are not absolute. It might be that a child is more impaired in one domain than in another or that they fall on the border between levels. It is also true that children at different levels might have similar needs.

In addition to these challenges experienced by learners with intellectual disabilities, there are environmental barriers which further hamper their participation in a stimulating environment.

Barriers experienced by learners with intellectual disabilities and the impact on caregivers

The barriers experienced by learners with intellectual disabilities can be categorised as systemic, environmental, social or attitudinal. These barriers are intertwined and do often not exist in isolation, making them all the more challenging to address.

Systemic barriers

Systemic barriers are existing laws and policies that unfairly discriminate against and impede people with disabilities from participating in particular activities. Policies intended to support learners with intellectual disabilities, but which fail in terms of implementation and the level of understanding required, also present a systemic barrier (**Kleintjes et al., 2020**; **McKenzie et al., 2013**).

The adoption of rights-based methods to service delivery for people with disabilities is strongly encouraged by international and local legislation. People with intellectual disabilities are included in the policies, but these policies are often not implemented effectively due to inadequate consideration of needs and the circumstances in which people with intellectual disabilities find themselves. People with intellectual disabilities, particularly those with SPID, are therefore often excluded from service delivery as a result of decision-makers' limited understanding of their needs (**Kleintjes et al., 2020**).

For instance, interacting with others is a trait that characterises humans. However, despite the fact that communication is highlighted in policy and legal frameworks as a fundamental human right, but is frequently denied to children with SPID who struggle with communication challenges and need to attend special care facilities, particularly in under-resourced settings (**Geiger, 2012**).

Environmental barriers

Environmental (or physical) barriers that prevent people with disabilities from actively participating in society can be characterised as either internal or external, include physical obstacles like doorways, architectural features and room arrangements.

Internal environmental variables refer to elements in the homes and educational facilities; whereas external environmental factors refer to aspects in the community and how the accessibility of the surroundings affects the involvement and learning for learners with intellectual disabilities (**Kleintjes et al., 2020**; **McKenzie et al., 2013)**.

External environmental barriers

The development and participation in activities for children with SPID can be impeded by a variety of external environmental factors. For instance, public parks, libraries, shops and roadways can make it difficult or even unsafe for the child to engage or explore the space if they don't provide accommodations for the needs of children with intellectual disabilities, such as ramps for wheelchair access and railings to assist mobility. Due to these barriers, learners with SPID are excluded from social activities (**Ahmad, 2012**).

Environmental constraints also make it very difficult for people with intellectual disabilities to take care of their basic healthcare requirements. These constraints include unhealthy and environmentally compromised living circumstances, unsafe living conditions and transportation routes that are difficult to manage without assistance. The extensive distances people need to travel to access health services and the expense involved is also a fundamental barrier to a healthy lifestyle and social interaction (**Kleintjes et al., 2020**; **Mkabile & Swartz, 2020**).

These barriers can also be one of the reasons why parents refuse to let their children attend special care centres; thereby depriving them of access to stimulating activities hampering their development (**Ahmad, 2012**).

Internal environmental barriers

Internal environmental barriers refer to infrastructure in the home. The availability of bathrooms, running water, electricity, walls, short hallways, stairs or even the placement of furniture can limit what a child is exposed to (**Ahmad, 2012**).

Social barriers

Social barriers result from limitations within people's environments that hinder their ability to live, learn and work. Social barriers that limit access to resources, opportunities or locations have an effect on people's health and well-being (**Kleintjes et al., 2020**; **McKenzie et al., 2013**).

Attitudinal barriers are a kind of social barrier caused by how people view people with disabilities. It is no secret that society frequently harbours prejudice and discrimination against people with disabilities. Society often treats people with disabilities with fear, pity, and contempt and tries to avoid them. These barriers are often brought about by a lack of knowledge and false assumptions about people with disabilities (**McKenzie et al., 2013**).

In order to gain a better understanding of the attitudinal barriers to learning experienced by learners with intellectual disabilities, watch the following video.

WATCH: TEDI 4 week 2 – Attitudes to learning ○

Creator: Anthea Hansen
Date: 2019
Duration: 11 minutes

The impact of barriers on caregivers

As these barriers demonstrate, lifelong care is inevitable for persons with SPID and they need a high level of support to access services and participate in societal activities (**Modula, 2022**). Caregivers play a pivotal role in this regard.

Caregivers are defined as individuals who provide care to any person who is unable to provide care for themselves. They can provide services formally or informally. Unpaid caregivers, such as the parents and family members of children with disabilities, provide informal services. Caregivers who are paid, such as staff at special care centres, provide formal services (**Moosa-Tayob & Risenga, 2022**). Primary caregivers of persons with SPID are typically solely responsible for providing support.

Due to the high level of ongoing support required by persons with intellectual disabilities, caregivers can feel very burdened, resulting in high levels of stress (**Modula, 2022**). Caregivers are also affected by the barriers affecting those with intellectual disabilities, which can exacerbate the level of burden and stress levels they experience and have a potentially negative impact on their own quality of life. This could, in turn, influence the quality of care they provide persons with intellectual disabilities (**Modula, 2022**; **Kleintjes et al., 2020**).

In our discussion on the history of intellectual disability at the start of this chapter, we highlighted some of the negative beliefs communities hold about persons with intellectual disabilities. This kind of stigma in communities with high levels of violence can result in caregivers fearing for their safety and for the safety of their own children as well as those they are caring for (**McKenzie et al., 2013**).

State grants for care dependency and disabilities are frequently the only source of income for households with children who have intellectual disabilities. In some cases, due to the small amount received in these grants, caregivers need to utilise their own limited resources in order to cover additional expenses like transportation, making participating in activities like learning, working and getting healthcare services difficult. Because of the frequently restricted financial resources caregivers have, both the person with an intellectual disability and their caregiver are unable to participate actively and equally in society, which has an effect on their health and welfare (**Modula, 2022**; **Mkabile & Swartz, 2020**).

Despite the fact that policies for persons with intellectual disabilities do not always translate into practices, their needs are taken into consideration. Caregivers' needs, on the other hand, are seldom considered. Caregivers report elevated levels of stress which are made more difficult by these barriers and do not receive support to lessen the level of caregiver stress (**Mkabile et al., 2021**). In their daily lives, they can feel abandoned and unsupported by healthcare providers, government and their communities. The wellness of the person with an intellectual disability can also be put at risk as a result of a decline in the caregivers' mental and physical health caused by a lack of assistance. Financial, social and emotional support should be given to caregivers and the care recipient in order to promote their well-being (**Moosa-Tayob & Risenga, 2022**).

Research demonstrates that mainstream healthcare providers' stigmatising behaviours can prevent people with intellectual disabilities from accessing the quality care and education they are entitled to (**Mkabile & Swartz, 2020**).

REFLECTION

In this reflection activity, Marlene le Roux shares the intimate details of her experiences as a mother of a child with an intellectual disability – her experiences with the medical fraternity, religious communities and the emotional highs and lows.

A huge barrier was how the medical fraternity reacted, like the doctor very coldly told me that I must put Adam in a home. I can still feel, I can still taste. I know exactly the day, the date, the time.

How the medical fraternity reacted, each one acted separately and not in coordinated, holistic way. I received advice and information in a fragmented way. For example, the speech therapist would tell me I must feed Adam in this way to stimulate him so that he can make sound. I would then go to occupational therapists that would show how to use the mouth in order to stimulate inside. From there, I would go to the physio, and get different advice.

And when you go home as a mother, you feel so despondent because one will say you must use the spoon in this way. The tongue you need to press down, the finger, you must… At the end when you go home, you just do your own thing because, number one, you feel so tired.

Secondly, you feel sometimes so despondent because what they never asked you as the mother is, how do you feel? How did Adam respond to the treatment that Adam and you had or you had as the carers as well? So the fragmentation of the medical fraternity should be much more a team approach, holistic approach. Where family members, where caregivers can be given specifically advice together in order for the specialist to work together in a team so that after the two hours that you spend with all these therapists, that you as a team that goes home where family members can understand what is nutrition, what must be mashed.

With regards to the hospital, that we frequented, I found that even the staff themselves were not treated and trained properly how to deal with a person who's extremely and profoundly disabled. People didn't talk to him; they ignored him and Adam fully sensed who was around him.

When he was hospitalised, I used to stay 24 hours a day with him. Why? To help with feeding him, turning him every two hours, because he couldn't talk or ring a bell.

Also being disabled myself, people were asking me straight in my face. Why did you have a second child? Look what happened to you.

People used to come and pray. And I need to say this is not a prayer thing. I've accepted Adam. And I loved him unconditionally. Some of my own family members, I had no clue of the challenge that I faced every day, giving medicine, getting him to the physiotherapist, the speech therapist, feeding him, which took two hours every time.

To hear the rest of Marlene's story, watch the full interview on the **OpenUCT** website.

REFLECTION

Think about Marlene's experiences as shared and reflect on the importance of the family-professional partnerships for caregivers and their children with intellectual disabilities.

Conclusion

Children and adults with SPID will never attain full independence, unlike those with milder forms of intellectual disability, and are in need of lifelong care. This means that we cannot consider their well-being without thinking about the well-being of their caregivers. This is why we talk about circles of care and education. Just as the child will need support to flourish throughout their lives, so too do their caregivers need support – circles around each other that allow the child to achieve the best quality of life and to reach their own and full potential. These circles of care are critical in supporting the education of children with intellectual disabilities.

The learner has an influence on these circles of care and is affected by what happens within these circles of care (**Adnams, 2016**). In the **next chapter**, we will further explore the concept of circles of care along with implementation of UDL to support learners with intellectual disabilities and the importance of human rights for these learners.

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