chapter 21

Disability Studies in Inclusive Education

Learning support, curriculum adaptation and human rights for learners with intellectual disabilities

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Chapter learning outcomes

After completing this chapter, you will be able to:

- Describe the different kinds of learning support needed for learners with intellectual disabilities to participate in education.
- Identify barriers to learning experienced by learners who have intellectual disabilities, particularly those with severe to profound intellectual disability (SPID).
- Apply teaching strategies for inclusive learning in your own educational context for learners who have different levels of intellectual disability.
- Analyse how the principles of Universal Design for Learning (UDL) can be used to create conducive learning environments for learners who have intellectual disabilities.
- Explain the importance of human rights and legal issues for learners who have intellectual disabilities, particularly those with SPID.

Preparatory activities

WATCH: The moral significance of being human

Creator: The Malta Foundation for the Wellbeing of Society
Date: 2018
Duration: 8 minutes

WATCH: Peter Singer: I disagree with The Universal Declaration of Human Rights

Creator: Premier Unbelievable?
Date: 2018
Duration: 8 minutes

This video may be upsetting to some viewers.

REFLECTION

In a *Guardian* interview, Peter Singer states:

Just as we accept that race or sex isn't a reason for a person counting more, I don't think the species of a being is a reason for counting more than another being. What is important is the capacity to suffer and to enjoy life. We should give equal consideration to the similar interests of all sentient beings. Defenders of speciesism argue that humans have a special rational nature that sets them apart from animals, but the problem is where that leaves infants and the profoundly intellectually disabled. Instead of defending the idea that all humans have rights but no animals do, we should recognise that many things we do to animals cause so much pain and yet are so inessential to us that we ought to refrain. We can be against speciesism and still favour beings with higher cognitive capacities, which most humans have – but that is drawing a line for a different reason. ***If there are animals that have higher cognitive capacities than some humans, there's no reason to say that the humans have more worth or moral status simply because they are human.***

Do you agree with the argument for animal rights put forward by Peter Singer? How do you feel about the statement highlighted in bold above?

Introduction

As discussed in **Chapter 20**, there are different types and levels of intellectual disability which require different degrees and types of support. The kind of support required is unique to every child and varies in intensity, depending on the need of the learner. Supporting learners with intellectual disabilities requires family-school partnerships and a collaborative effort between government departments (**Adnams, 2016**).

In this chapter, we focus on children with intellectual disabilities, recognising that they can learn when they are given the right opportunities to do so, but are often the most neglected of children, including the disabled, in the education system. With a focus on the South African context, we will gain an understanding of the kinds of support that can help learners with intellectual disabilities to learn. We will also consider a number of complex factors relating to their human rights.

Learning support to address barriers to learning encountered by learners with intellectual disabilities

Learners with intellectual disabilities is a much neglected cohort within the South African educational system (**McKenzie et al., 2018**).

The South African Department of Basic Education (DBE) (**2018**) Draft National Guidelines for Resourcing an Inclusive Education System stipulates that special schools are required to provide support in the following ways:

- Provision of specialist services by specialised professional staff.
- Curriculum differentiation, including adjustments and accommodation in assessment.
- Provision of specialised learning and teaching support materials and assistive technology devices.
- Training and mentoring of teachers, managers and support staff.

Despite these policy efforts, issues remain around the implementation of these policies, particularly for learners with SPID.

In South Africa, while some learners with intellectual disabilities attend special schools, many learners with SPID or multiple disabilities are not accepted at special schools. They are therefore forced to either remain home or attend informal special care centres formed by their guardians. These special care centres are valuable, but are mainly focused on caring for, rather than educating, learners. This means that many learners with SPID are denied their right to formal education (**Taylor et al., 2016**).

In the shift towards an inclusive approach, mainstream schools make adaptations so that they can function as "full service schools" and accommodate learners with mild to moderate intellectual disabilities. The process of deciding whether a learner with an intellectual disability attends a special school or a full service school, entails an important conversation between parents, teachers and the learner. Many special schools find themselves accommodating an increasing number of learners with mild intellectual disabilities whose needs have not been met in mainstream schools (**Taylor et al., 2016**).

GLOSSARY: Full service schools

Full service schools are ordinary mainstream schools that are inclusive and welcoming of all learners in their cultures, policies and practices. "Full service schools increase participation and reduce exclusion by providing support to all learners to develop their full potential, irrespective of their background, culture, abilities or disabilities. These schools should be strengthened and orientated to address a full range of barriers to learning in an inclusive education setting to serve as flagship schools for full inclusivity" (**Taylor et al., 2016, p. 56**).

An individual support plan (see Table 1) is useful in determining the areas in which the learner requires support and the degree of support they require in navigating their journey through a learning programme (**Teacher Empowerment for Disability Inclusion [TEDI], 2019**).

Table 1: Areas of support and factors for consideration in developing an individual support plan

Area of support	Factors for consideration in individual support plans
Educational	Degree of support needed during exposure, exploration, attainment and participation in activities (e.g. hand-over-hand support to explore toys).
Functional	Degree of support needed for the learner to be mobile or for communication purposes (e.g. requires walking frame to walk 10m).
Activities of daily living	Degree of support needed for dressing, toileting and feeding (e.g. holding a cup with handles).
Behavioural	Details about the learner's fixed routine and daily programme, use of quiet areas, etc.
Medical	Details about medication, referrals to doctors, liaison with parents, etc.
Assistive devices	Details about the checks, maintenance, review and referral of assistive devices to the Department of Health and other providers.
Classroom	Details about the use of classroom elements (e.g. ability grouping available equipment and resources, and navigating layout of classroom areas).
Centre	Details about equipment (e.g. ramps, nappy changing areas and carer-child ratio).
Family and carer	Requirements for counselling, support groups and workshops.

For learners with SPID, developing an individual support plan is particularly important and it is a team effort requiring contributions from the learner, the carer, family members, therapists, doctors and social workers. The collective contribution facilitates the development of a realistic plan that identifies how the learning programme can be adapted according to the needs of the learner (**Bosch, 2016**).

Learning support for learners with mild to moderate intellectual disabilities

Learning support for learners with mild to moderate intellectual disabilities will not be covered in this section.

We are focusing on the support needs of learners with SPID. The learners with mild to moderate intellectual disabilities might not have the same support needs. For further information on the support needs of learners with mild to moderate intellectual disabilities, please refer to Kurth (**2013**).

Learning support for learners with SPID

"**The Severe to Profound Intellectual Disability: Circles of Care and Education**" Massive Open Online Course (MOOC) highlights the following different kinds of support needed by learners with SPID:

- **Emotional** support to foster a sense of acceptance.
- **Financial** support, including resources such as assistive devices and disability grants.
- **Physical** support with daily activities, such as eating meals.
- **Learning** support in smaller classes that provide educators with the opportunity to provide more supervision.
- **Social** support to feel included by others.
- **Legal** support through policies the protection of their rights.

The purpose of support is to ensure that learners can fully participate in society and make use of their abilities, resources and opportunities. For learners with SPID, it is important to note that their needs, the kind of support required and duration of support varies. While many may require high levels of constant support on a permanent basis, others may need less. Support should be tailored according to the individual's needs, age and frequency required (**Coetzee & Johns, 2016**).

This group is heterogeneous and divided into three broad learner groups according to their ability to participate in daily activities; namely: awareness, transitional or interactive (**DBE, 2016a**). Table 2 provides an overview of the groups, examples of learner behaviour that characterise these groups and the kinds of assistance learners may require.

Table 2: Examples and types of support required for learners with intellectual disabilities

Awareness group	Transitional group	Interactive group
Inactive, withdrawn and/or sleepy.	Smiles when smiled at and shows brief interest in toys.	Active and focused on the environment.
Needs full support to facilitate attention to the environment.	Needs assistance to maintain attention, respond and engage in activities.	Needs support and supervision.
Can be agitated.	N.A.	Ready to participate and open to learning.

Support needs can be met by various people. It is important that relevant role-players carefully assess the support needs of the learner and use their different perspectives and skills during all stages of someone's life (**McKenzie, 2019a**). Support needs to be provided within the local community, the wider community and in the broader social system as a whole (**McKenzie, 2019b**). These layers of support are what we refer to as the "circles of care" (Figure 1).

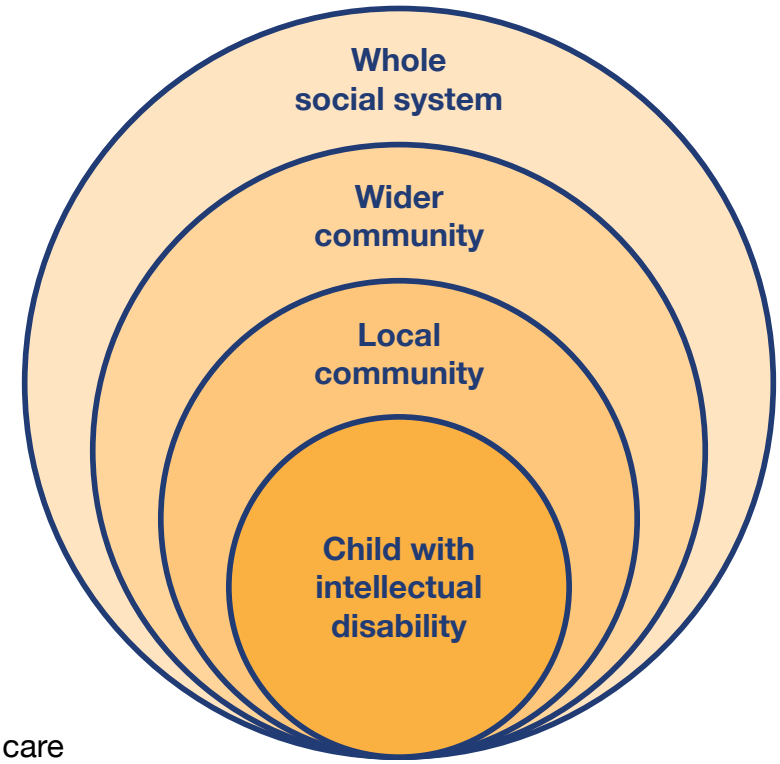

Figure 1: Circles of care

Figure 1 depicts the levels of support from the circles of care around the child. The child is at the centre of the circle. Family, carers, healthcare professionals and special-care centres form the local community. In the wider community, we have friends, neighbours, businesses and organisations. The social system includes policies and legal frameworks. The players in each of the circles are connected and affect each other. The learner has an influence on these circles of care and is affected by what happens within these circles of care (**McKenzie, 2019a**; **McKenzie 2019b**).

WATCH: Inclusive education for children with intellectual disabilities in Kenya

Creator: UNICEF Kenya
Date: 2017
Duration: 7 minutes

The use of assistive technology devices and specialised equipment should also be considered in developing an individual support plan.

Use of assistive technology devices and specialised equipment

Assistive technology devices are useful in supporting the development of learners with intellectual disabilities, in general, but play a particularly important role in ensuring that learners with SPID receive the support they require.

Independence and participation in teaching and learning activities can be increased for learners with SPID through the use of these devices, which compensate for learners' skill deficits or areas of disability and contribute to the development of their self-reliance and sense of independence. With the help of these devices, learners can work independently rather than being overly dependent on parents, siblings and friends. Assistive technology devices can be used to not only enhance learning, but also to improve their activities of daily living and, therefore, their independence (**TEDI, 2020**).

Table 3 presents a list of conditions associated with SPID and the supportive assistive technology devices and specialised equipment that can be used in each instance.

Table 3: Impairments and supportive assistive technology devices for learners with SPID (Adapted from: **TEDI, 2020**)

Conditions associated with SPID	Examples of suitable assistive technology devices and specialised equipment
Neurological and neurodevelopmental impairments	• Literacy software for reading and writing support • Mathematics development software • Text-to-speech devices • Sensory development resources
Cognition and learning impairments	• Mouse skills software • Keyboard skills software • Literacy and numeracy development software • Mind-mapping software
Communication impairment	• Portable voice amplifier • Message recordable devices • Picture symbol software • Text-to-speech devices
Learners who are D/deaf or hard of hearing, and/or blind or have low vision	For those who are blind: • Braille technology • Low- and mid-tech devices for tactile learners • Non-optical low vision devices • Video magnifiers For those who are D/deaf: • Frequency modulation system • Induction loop system • Personal sound amplification device • Remote interpreting

Using UDL and curriculum adaptation to create conducive learning environments

Meaningful participation of all students in general or mainstream education can occur through the use of a range of strategies. Applying the principles of UDL ensures that the means of instruction employed by teachers support different ways of learning, expressing and engaging, thus facilitating greater opportunity for educational success for the learner with an intellectual disability (**Kurth, 2013**).

General curriculum adaptation through the application of UDL principles should be employed in a classroom to avoid students feeling isolated. Employing general curriculum adaptation principles such as UDL allows educators time to focus on creating specific adaptations, bridging the gap between skills and needs. Educators do, however, also need to be careful not to over-adapt, which could result in the stigmatisation of the learners who require adaptation (**Kurth, 2013**).

WATCH: UDL: Principles and practice

Creator: National Center on Universal Design for Learning
Date: 2010
Duration: 7 minutes

READ: A unit-based approach to adaptations in inclusive classrooms

Author: Jennifer A. Kurth
Year: 2013
Estimated reading time: 90 minutes
File size: 219 KB

For learners with intellectual disabilities, it is important to employ a general curriculum adaptation strategy such as UDL to create specific adaptations and include the use of technology (**Kurth, 2013**). Table 4 provides examples of ways in which teachers can give effect to the UDL principles of multiple means of representation, action and expression, and engagement, which can benefit learners with intellectual disabilities. This table is drawn from presentation by Taryn du Toit from Cape Mental Health.

Table 4: Examples of how to effect principles of UDL

UDL principle	Examples of how to effect principles of UDL
Multiple means of representation	• Clear and simple language • Select culturally sensitive activities and materials • Use visuals/gestures and demonstrations • Use concrete and tangible objects, hands-on activities • Break down the curriculum into components • Use repetition regularly • Use different sensory inputs (visual, auditory) • Scaffolding (guidance and support given graded over time)
Multiple means of action and expression	• Adapt assessments: use images, scribing, laptop • Vary assessment questions: MCQs, short answers • Create different assessment options: oral/poster/essay • Allow time for their response • Encourage interaction, group work • Use role-playing, games and demonstrations • Adapted response materials: cloze statements, word banks, etc. • Augmentative and alternative communication
Multiple means of engagement	• Minimise distractions • Paraphrase what they are saying • Provide immediate feedback on their progress • Work within their attention span range • Be positive, use humour and make learning fun • Encourage mutual respect and trust • Build a rapport with them • Encourage participation and feedback from learners • Use activities and role-play and involve the learners • Set goals with the learners • Group work activities or working in pairs • Give regular breaks • Create tension free and open environment • Make the learning relevant and relatable to them • Assistive devices, specialised equipment and teaching and learning support

The development of individual support plans can be combined with and integrate the use of relevant technologies to support the inclusion and the individualisation of learning paths for students with intellectual disabilities (**Frolli et al., 2020**).

Technology plays an important role in creating an accessible curriculum for learners with intellectual disabilities. Table 5 provides examples of assistive technology devices for learners with severe to profound intellectual disabilities that enable the implementation of UDL principles.

Table 5: Assistive technology devices for learners with SPID that enable implementation of UDL principles (Source: **TEDI, 2020**)

UDL principle	Assistive technology devices
Representation	**High-tech**
Enabling multiple ways of presenting content	• Literacy development software • Specialised e-reader • Picture symbol software
Expression	**Mid-tech**
Enabling learners to communicate what they know and can do through various means	• Alternative large keyboard • Colour-coded mouse • Mouse skills software • Talking calculator
	High-tech
	• Multimedia player • Literacy, numeracy, science, creativity curriculum activities software • Simulation software for maths, science, technology, computing, automotive skills • Inclusive interactive music system
Engagement	**Mid-tech**
Enabling the facilitation of choices of learning activities to cater for the varied abilities of learners	• Screen-reading software • Literacy, numeracy, science, creativity curriculum activities software • Mind-mapping software • Simulation software for maths, science, technology, computing, automotive skills • Inclusive interactive music system

UDL emphasises the importance of building expert learners in any context. Learning and expertise are continual processes that involve practice, adjustment and refinement. CAST defines expert learners as purposeful and motivated, resourceful and knowledgeable, and strategic and goal directed (**CAST, 2018**). Learners can become expert regardless of the severity of their support needs. It is important to note that being an expert learner is not about mastering content, but rather about turning everyday experiences into opportunities to learn and develop. Educators who recognise that their learners are resourceful, strategic and motivated build on students' expertise and in this way encourage mastery of knowledge (**Hartmann, 2015**).

Hartmann (**2015**) provides the following example of Marcus, a learner with an intellectual disability who can been described as an expert learner:

> *Marcus, a soft-spoken teenager was born prematurely. He is a tall, happy guy with multiple support needs. He has multiple impairments, including intellectual disability, visual impairment, seizures, cerebral palsy, and speech and language impairment. Despite his impairment, his teacher recognises that Marcus is an expert learner because he actively experiences life and learns from it. He is purposeful in how he seeks out and finds his close friends on entering the room. He is resourceful in how he uses touch to explore and understand new materials and spaces around the classroom. He is strategic in how he verbally asks for preferred activities but does not respond to questions about activities he didn't enjoy.* (**Hartmann, 2015**)

Table 6 presents expert learner characteristics and examples of Marcus as an expert learner in practice.

Table 6: Expert learner characteristics and examples in practice (Source: **Hartmann, 2015**)

UDL principle	Expert learner characteristics	Examples of an expert learner in practice
Multiple means of engagement	Purposeful, motivated learners	Marcus enjoys being with his peers and learns best when paired with a friend. He listens closely to their words and likes to repeat back what they've said.
Multiple means of representation	Resourceful, knowledgeable learners	Marcus learns best by tactually exploring materials. When auditory information is paired with tactual information, he learns new concepts.
Multiple means of action and expression	Strategic, goal-directed learners	Marcus clearly and skilfully communicates his preferences. He vocalises loudly and clearly when he knows his communication partner and is given two or three choices.

ACTIVITY

Estimated time: 25 minutes

Plan a lesson for a class you are currently teaching (or a class you have previously taught in) on one of the following two topics:

- Keeping safe during an emergency.
- Making the world around us a cleaner place for all.

Your class includes three learners with different levels of intellectual disability. One has severe cerebral palsy and profound intellectual disability and uses a wheelchair, as she cannot move her muscles in her arms and legs. She also has difficulty speaking. The other two learners joining your class have moderate intellectual disabilities and full mobility.

1. Outline the teaching strategies you will use to include all learners, highlighting the practical ways that you will implement UDL guidelines so that all learners in the class will benefit.
2. Outline the teaching strategies you will use to include all learners (i.e. the specific adaptations and support you will provide during this lesson).

You can do this activity individually or in small groups of three to four people.

The importance of human rights and legal issues for learners with intellectual disabilities

Despite international policies and frameworks, such as the *Convention on the Rights of Persons with Disabilities* (2006) and the social model of disability, it has been argued that the limited gains made through a rights-based approach to disability have been less effective for people with intellectual disabilities than people with other disabilities. Bozalek et al. (2014) point out that this can be attributed to the disability movement's focus on autonomy

and independence, rather than care. In this context, care has been construed as a form of domination and power exercised by families and service providers over people with intellectual disabilities (**Bozalek et al., 2014**).

Human rights approaches for intellectually disabled people have not given sufficient consideration to the complexity of rights claims made by and on behalf of people with intellectual disabilities. Human rights becomes problematic when it assumes that all individuals are free, equal and independent. Applying this criteria to people with intellectual disabilities is problematic; in that if the person is incapable of knowing the law, the person cannot be free. Equality requires that the person possess reason and independence requires that the person is not dependent on another. Many people with intellectual disabilities have a lifelong dependency on others (**Bozalek et al., 2014**).

As a result of the limitations faced around cognitive ability and dependency, learners with SPID have traditionally been excluded from education on the basis that they are ineducable. In 2010, the Western Cape Forum for Intellectual Disability challenged this notion through litigation against the government (**McKenzie et al., 2017**). The court declared that every child in South Africa who has SPID has the right to education and must have access to basic, quality education. As a result, the government was directed to take reasonable measures in order to give effect to the rights of learners with SPID, including: affordable, accessible, quality education; adequate funding and facilities; and training and remuneration for staff at special care centres (**McKenzie et al., 2017**).

Steps have been taken and policies such as the DBE *Daft Policy for the Provision of Quality Education and Support for Children with Severe to Profound Intellectual Disability* (**DBE, 2016b**) "recognise[s] the complex needs of these children and their families who require a person-centred, holistic and integrated approach that will ensure the maximum development of each child's individual potential" (**DBE, 2016b, p.15**).

Challenges with disparities in policy implementation

The South African government has developed educational policies to support learners with disabilities, but many do not adequately consider the inclusion of learners with intellectual disabilities, particularly SPID. This is largely due to an inadequate understanding of these learners' needs. A disparity between the policies and their practical implementation resulting from a failure of leadership has also resulted in inadequate support within educational systems promoting education for all (**McKenzie et al., 2018**).

Disparity between policy and implementation has also resulted from a lack of funding, which has led to a lack of resources for the accommodations required to meet the needs of learners with

intellectual disabilities. In addition to disparity between policy and implementation, there is also disparity between policies that pertain to learners with intellectual disabilities versus learners with other kinds of disabilities. The consequence thereof is inadequate teacher training and a lack of opportunities for teachers to advance their disability practice. The lack of academic teacher-training programmes results in teachers having negative perceptions of learners with intellectual disabilities and a lack of understanding of these learners' needs. Limited teacher training programmes also make curriculum adaptation challenging, resulting in the curriculum not being inclusive of the needs of learners with intellectual disabilities and therefore posing an additional barrier to learning. For learners with intellectual disabilities, curriculum adaptation is imperative to their inclusion in the education system (**McKenzie et al., 2018**).

By now, you should be familiar with international and local policies recognising the rights of all children to quality education. Even though these policies and frameworks are explicit in the acknowledgement of the right to education for all, many children with intellectual disabilities remain excluded from mainstream education and the special education system (**WCFID Right to Education Task Team, 2016**).

While we continue to advocate and lobby for the rights of learners with intellectual disabilities to inclusion, learners with SPID have yet to be accommodated in terms of their needs and rights to education and development.

WATCH: TEDI 4 week 4 – Ethics of care-giving and receiving

Creator: Judith McKenzie
Date: 2019
Duration: 10 minutes

READ: Rights discourses in relation to education of people with intellectual disability: Towards an ethics of care that enables participation

Author: Judith McKenzie & Catriona Macleod
Year: 2012
Estimated reading time: 2 hours
File size: 223 KB

ACTIVITY

Estimated time: 20 minutes

Once you have read the paper by McKenzie and Macleod (**2012**) above, make notes on your reflections. The methodology is rather complicated, so focus more on the discussion and findings.

Conclusion

In this chapter, we explored the barriers experienced by learners with intellectual disabilities, as well as the role societal attitudes and policies play in excluding learners with intellectual disabilities from receiving quality education. We discussed circles of care and the important role family, neighbours, community, health professionals and policy-makers play in providing learning support to learners with intellectual disabilities, particularly those with SPID. We also took a look at the types of assistive technology devices and specialised equipment available as a form of learning support.

We showed how UDL principles can be used to benefit the development of learners with intellectual disabilities. Given the right opportunities and support, learners with intellectual disabilities are able to develop and meaningfully participate in education and society as a whole.

Finally, we explored the complexities of adopting a rights-based approach to the inclusion of people with SPID and some of the tensions between policy development and implementation.

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