chapter 19

Disability Studies in Inclusive Education

Overview: Intellectual disability, impact on learning and learner support

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Section learning outcomes

After completing this section, 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.
- ✓ 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 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.

Introduction

In this section, we cover the nature of intellectual disability, the effect of intellectual disability on learning for the child with an intellectual disability, and related educational and legal issues. There are different levels of intellectual disability and these levels have different implications for the barriers learners with intellectual disabilities encounter in trying to obtain an education; which in turn has significant implications for the roles their caregivers need to play. We take a particular focus on a neglected group, which is learners with SPID, their right to education and the implications barriers to care and education have on the lives of their caregivers and families.

Learners with milder forms of intellectual disability may not need the high levels of support described in these chapters; therefore, the implications would be different and the barriers to education experienced by these learners and the implications for their families would be varied.

In **Chapter 20**, we unpack the nature, effect and levels of intellectual disability. We explore the barriers experienced by learners and the impact they have on caregivers and parents, with a particular focus on learners with SPID. Caregivers are given a voice revealing their experiences as caregivers of learners with SPID in the South African context.

Caregivers play a pivotal role in the lives of children with intellectual disabilities, especially in the lives of children with SPID. Caregivers of learners with intellectual disabilities range from paid to unpaid, formal and informal, family members or even health therapists. Whether they are family caregivers or caregivers at special care centres, they are indispensable to realising the rights of persons with intellectual disabilities. By the very nature of their condition, people with SPID find it difficult to meet their personal needs and assume social responsibility in certain aspects of their daily living. The lifelong responsibility to care for and support a person with an intellectual disability falls on those involved in their lives.

In **Chapter 21**, we explore strategies for learner support and curriculum adaptation to accommodate learners with SPID in relation to the barriers these learners face. We also examine the disjunct between the experiences of caregivers and the policies and human rights frameworks and how caregivers are not given sufficient priority in policies, research and practice in South Africa.

In the insider view presented below, Taryn du Toit conducts an interview with Eliz-Mari Williams, a caregiver at the Centre for Caring and Sharing in Touwsrivier in the Western Cape, on her experiences as a caregiver of learners with SPID.

WATCH: Support needs: A caregiver's perspective ○

Creator: Taryn du Toit & Eliz-Mari Williams
Date: 2019
Duration: 13 minutes

Insider view: Perspectives on education

Eliz-Mari has worked with children and teenagers with SPID, predominantly foetal alcohol syndrome, for eight years. A typical day for Eliz-Mari begins with checking the children's emotional moods; followed by gross motor, fine motor and cognitive development activities. She describes each day as "an adventure" informed by the needs of the children. Her challenges include building up the children's self-esteem to accept their disabilities while confronted with the small-town, societal stigma surrounding the word "disability".

"See me before you see my disability" is a mantra Eliz-Mari and the other carers share with the children to bolster their self-esteem. Much like the children she cares for, Eliz-Mari was a shy, unconfident child, but with the children's pure, unconditional love for her, her self-esteem has improved, making her who she is today. Her motivation to care for the children comes from her belief that her community's children are her children and that someone needs to step up and care for them.

Eliz-Mari works to decrease the community stigma towards people with disabilities by hosting educational sessions and talent shows starring the children; she also involves the children in the community through activities, such as taking the teenagers grocery shopping. One of the benefits of involving the community in the children's lives is an improvement in their self-esteem to continue confidently interacting with the community. There is a large, positive impact on the children's well-being when they feel accepted and involved in the community. Therefore, Eliz-Mari encourages the children to make friends with children outside of the care centre.

The support the children receive includes physical support, learning support and social support. Eliz-Mari and the other carers have a system for providing physical support, in which the child first tries the activity on their own and the carers assess where assistance is required. This process is informed by the principle that the child needs to be as independent as possible. Physical support includes repetition of activities, engaging the children in sensory stimulation and always finding a way to involve the children in activities. Building trust with the children is important for Eliz-Mari. For example, before helping a child put on their shoes for the first time, she asks them to help her put on her shoes. She then shows them how to put on the shoes and asks them to try put on their own shoes.

The areas of support provided by the care centre address the social, emotional, financial and legal needs of the children. Eliz-Mari strives to provide social and emotional support because she wants the children to accept themselves as strong, independent people and to be part of the community. The centre welcomes community members to come and learn about SPID, on condition that they treat the children respectfully. The centre also has a social worker who provides legal support. On occasion when the social worker is unable to act immediately, Eliz-Mari and the other staff go to the police. Oftentimes the police are uncooperative, especially

because a child with an intellectual disability is involved. Eliz-Mari is determined to help the children, so she remains at the police station until the police assist her.
Her persistence has been noticed by the police, so they are now more proactive in processing the cases she brings. In terms of financial support, most of the children receive social grants which pay for their attendance at the care centre; for those children who do not receive grants, the carers organise fundraising or cover the payments themselves.

Eliz-Mari and the care centre team work consistently to provide individualised care based on each child's needs, often discussing the way forward for each child. The children's parents are also involved so that the individually adapted activities continue at home. These activities are drawn from the ideas of the care centre team, a short course on special needs that Eliz-Mari attended and the **Teacher Empowerment for Disability Inclusion** free online course.

Eliz-Mari feels rewarded seeing the children accomplish developmental states unique to their abilities, regardless of the timeframe required to achieve these goals. Eliz-Mari asks for non-disabled people to see the humanity of children with disabilities before seeing their disabilities. She notes that non-disabled people expect children with disabilities to accept non-disabled people as "normal" and fully human, so she asks for non-disabled people to do the same of children with disabilities. Finally, Eliz-Mari challenges everyone to get to know a child with a disability, to see the child before their disability, and to accept the child for who they are, entirely.

REFLECTION

Estimated time: 10 minutes

Reflect on your personal response to engaging with children with intellectual disabilities. How does this experience make you feel and how do you treat the children? How does your personal response compare with your community's response to engaging with children with intellectual disabilities?