



Educating and Caring for Children with Profound Intellectual Disability

A manual for carers and teachers

Teacher Empowerment for Disability Inclusion (TEDI)

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Contents

Introduction	4
How to use this manual.....	5
Activities	7
Support activities.....	7
Acronyms.....	8
Key terms	9
CHAPTER 1: Understanding disability	13
1.1. What is disability?	13
1.2. Defining intellectual disability	14
1.3. Disability and inclusivity in society.....	17
CHAPTER 2: Acknowledging and supporting children with disabilities.....	22
2.1. Getting to know children with PID.....	22
2.2. Assessing children with PID	23
2.3 Communicating with children with PID	30
2.4. Playing constructively with children with PID	33
2.5 Working with assistive devices	39
2.6. Managing medical conditions	42
CHAPTER 3: Teaching and caring for learners with disabilities	43
3.1. Creating an environment conducive to learning.....	43
3.2. Developing individual support plans	50
3.3. Integrating a learning programme into a daily programme.....	55
3.4. Parental involvement with learning and the classroom	60
CHAPTER 4: Communicating with families affected by disability	61
4.1. What is effective communication?	61
4.2. Guidelines for improving communication.....	64
CHAPTER 5: Caring for the carer	68
5.1. Knowing oneself as a carer	68
5.2. Self-care in the workplace	70
5.3. Collaborative relationships in the workplace.....	74

CHAPTER 6: Using community and support networks	78
6.1. Belonging to a community	78
6.2 Building relationships with the community	80
CHAPTER 7: Understanding the wider context of disability	84
7.1. What is policy?	84
7.2. International policies and policy frameworks	84
7.3. National policies and policy frameworks	87
CHAPTER 8: Knowing more about specific disabilities	89
8.1. Introduction	89
8.2. Down syndrome	90
8.3. Cerebral palsy	90
8.4. Autism spectrum disorder	91
8.5. Foetal alcohol spectrum disorders	92
8.6. Global developmental delay	93
References	94
Appendix A: Physical development chart	96
Appendix B: Mental and social development chart	97
Appendix C: Cognitive milestones checklist	98
Appendix D: Positioning/Alignment checklist	101
Appendix E: 24-hour management checklist	102

Introduction

The Teacher Empowerment for Disability Inclusion (TEDI) project – headed by the University of Cape Town’s Disability Studies Division in partnership with Christoffel-Blindenmission (CBM), and co-funded by the European Union and CBM – aims to empower teachers and carers to provide quality education for learners with severe to profound disabilities through training focused on inclusivity, diversity and addressing learners’ disability-specific needs.

In 2018, TEDI piloted professional development courses and workshops for carers, teachers and other facilitators of learners with profound intellectual disability (PID). From these initiatives, a need arose to develop useful and practical resources for participants to enrich and further their learning. This manual is a response to that need, offering a practical, skills-based approach aligned with the Department of Basic Education’s policy framework and learning programme for learners with PID. The purpose of this manual is to:

- Provide a foundation of knowledge and skills.
- Promote skills to implement a learning programme for learners with PID.
- Provide basic knowledge for disability-inclusive development at both theoretical and practical levels.
- Supplement formal course learning and promote a practical approach to learning that includes discussions, activities, reflections and actions.
- Promote a collaborative approach to caring for children with PID among parents, carers and professionals, including learners with severe to profound intellectual disability (LSPID) support teams.

How to use this manual

This manual consists of eight chapters, which are outlined below for easy reference and can be used in conjunction with any course or workshop you may be completing.

CHAPTER 1: Understanding disability

This chapter covers topics relating to people's understanding and attitudes towards disability. It helps readers to understand the severity levels of disability and how to evaluate range of functioning. It explains the systems view of caring and educating children with disabilities using the Circles of Care model. It also considers various organisations' and individuals' roles in advocating for the rights of children with disabilities.

CHAPTER 2: Acknowledging and supporting children with disabilities

Chapter 2 explores what it means to get to know children with PID, and how to build solid relationships with them on which to base comprehensive and effective assessments. The process and criteria for assessing a child with PID is detailed using a multi-disciplinary approach. Some appropriate interventions are considered, with the focus on play and practical ideas to manage daily procedures and the effective use of assistive devices.

CHAPTER 3: Teaching and caring for learners with disabilities

Readers will find out more about the learning needs of children with disabilities and special considerations required to maximise their education. Information on how to create a physical environment suitable for learning is provided, along with guidelines on how to group learners according to their abilities. Further assistance is given on how to use the Department of Basic Education's Draft Learning Programme for Children with Severe to Profound Intellectual Disability (DBE, 2016a) in a daily programme, and how to adapt learning, play and other activities for groups of learners.

CHAPTER 4: Communicating with families affected by disability

This chapter concentrates on how families can be affected by a child's disability, and how a carer can assist their understanding of and ability to cope with the demands of PID. It helps to define clear communication and what it means to adopt a family-centred approach to caring for children with PID.

CHAPTER 5: Caring for the carer

Chapter 5 takes a closer look at the role of the carer, highlighting their exceptional worth and the work they do. It encourages carers to acknowledge the importance of their work and of self-care. Tips are given on how to cope with the daily pressures of working as a carer, the physical and emotional demands of the job, and how to manage stress and avoid potential burnout. Collaborative practice in the workplace is also discussed.

CHAPTER 6: Using community and support networks

This chapter considers the relationships children with disabilities have with people and organisations beyond their families and carers. It will look at the importance of community members having relationships with children with disabilities and the benefits these bring to everyone involved. Practical ideas are offered for ways to foster meaningful and mutually beneficial relationships with community members.

CHAPTER 7: Understanding the wider context of disability






Chapter 7 helps readers to understand how children with disabilities are part of a social system that is affected by the implementation of policies and legislation. It highlights some influential international and national policies and legislation that impact children with disabilities and their carers.

CHAPTER 8: Knowing more about specific disabilities

This chapter aims to equip readers with information about some of the most common health conditions and diagnoses affecting children with disabilities in South African communities.

Activities

Each chapter has a range of activities for you to complete. Some involve reading and reflecting on a story, while others require you to write down answers to specific questions. These activity icons indicate what you will need to do:

Icon	Activity type	What you need to do
	Read and reflect	Read the text or question(s) and reflect on how you can relate to the scenario or answer the question(s).
	Read and write/make	Read the text and/or the questions and write down your responses or make the suggested resources.
	Read and share	Read the text and/or the questions and discuss your answers or thoughts on the topic with a colleague who also works with children with PID.
	Investigate and learn	Using the link provided, read or watch the material about the topic.
	Read and learn	Use the suggested resource to read more about the topic.

Support activities

The Massive Open Online Course (MOOC) titled 'Severe to Profound Intellectual Disability: Circles of Care and Education' was developed by TEDI in conjunction with the Centre for Innovation in Learning and Teaching (CILT) at the University of Cape Town. This is a free, open access course that tells you more about children with PID and how you can help. You can do the course by yourself or in a group with other carers, teachers or therapists. To access the course you will need an Internet-enabled device (e.g. a personal computer, laptop, tablet or smartphone), a reliable Internet connection, and data to watch recordings and download the course materials.

To sign up for the course:

- Create a Coursera account using this link: <https://www.coursera.org/?authMode=signup>. You will be asked for your full name and email address, and to create a password. Once you have completed these details, navigate to the course and click on the 'Enrol' link.
- You will be offered two options: to sign up for free by enrolling for the full course with no certificate, or to purchase the course which will make you eligible for a certificate on successful completion. If you want to earn a certificate of completion, you will need to pay for the course using an electronic payment method, or apply for financial aid for a fee waiver.

You can then proceed to the course and start learning.

Acronyms

The following acronyms are used frequently throughout this manual. You may already know some of them. Familiarise yourself with any acronyms that are new to you and consult this list while working through the course.

AAC	Augmentative and Alternative Communication
ADL	Activities of Daily Living
CDG	Care Dependency Grant
CSPID	Children with Severe to Profound Intellectual Disability
DBE	Department of Basic Education
DoH	Department of Health
DSD	Department of Social Development
DSM-5	Diagnostic and Statistical Manual of Mental Disorders (Version 5)
EWP 6	Education White Paper 6 on Inclusive Education
ICF	International Classification of Functioning, Disability and Health
ISP	Individual Support Plan
LP	Learning Programme
LSPID	Learners with Severe to Profound Intellectual Disability
NCF	National Curriculum Framework
NCS	National Curriculum Statement
NELDS	National Early Learning and Development Standards
PID*	Profound Intellectual Disability
SIAS	Screening, Identification, Assessment and Support
SID	Severe Intellectual Disability
SPID**	Severe to Profound Intellectual Disability
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization
WPRPD	White Paper on the Rights of Persons with Disabilities

* *This term is used in this manual because the content is specifically directed towards this group.*

** *This is the term used in much of the South African policy and research. We understand it to mean the same as PID, but with a slightly broader scope.*

Key terms

Activities of Daily Living (ADL)	A series of basic activities performed by individuals on a daily basis that are necessary for independent living at home or in the community. These are also known as self-care skills (e.g. toileting, bathing, oral care, dressing and eating).
Augmentative and Alternative Communication (AAC)	AAC refers to all the ways we share our ideas and feelings without talking. It includes various methods to enhance communication using speech, gestures, signing, objects and pictures. We all use AAC every day in facial expressions or gestures instead of talking. People with severe speech or language problems may need AAC to help them communicate. AAC can help in school, at work, and when talking with friends and family.
Backchaining	This is a technique used to help children learn complex tasks or a series of tasks. The teacher begins with the last task, which is repeated by the child, and then gradually builds up the series of tasks by working backwards, step-by-step, to the beginning.
Baseline assessment	A review that identifies what a child is able or unable to do before any intervention has taken place.
Bilateral	Both sides of the body working together (e.g. movement of the arms and hands to clap).
Child centred	Focus is on the needs, strengths and interests of each child.
Cognitive development	The development of thought processes that start from childhood and include remembering, decision making and problem solving.
Co-morbid condition(s)	One or more additional disorders or medical conditions that occur with a disability.
Constant support	The child can be involved in an activity, but needs support throughout (e.g. the child can assist in getting dressed, but needs help to perform this task).
Duty of care	In the context of children with disabilities, the duty of care requires awareness and avoidance of the dangers of inappropriate physical handling, feeding and other care practices.
Education	Children with disabilities are able to develop skills, and can learn and apply knowledge with appropriate input. In this way, they can benefit from educational stimulation aimed at developing their maximum

	potential. Rather than developing academic skills, the focus is on communication, personal and self-care, and practical and conceptual skills within their natural daily environment.
Fully dependent	Cannot care for self and relies on someone to care for them (e.g. feeding, bathing, dressing).
Hand-over-hand support	The person teaching the skill places his or her hand over the child's hand and may manipulate the child's hand in performing the required action.
Holistic	The focus is not only on learning, but also takes into account the child's environment, including socio-economic circumstances and health status.
Inclusive education	Inclusive education is based on the premise that all children have the right to be welcomed and attend ordinary schools and early childhood development centres in their local communities. A supportive learning environment, including additional support where necessary, is provided to accommodate diversity so that all children are able to learn, contribute and participate in all aspects of the life of the centre or school.
Integrated approach	The subject components of communication and language, life skills and mathematics are not presented in isolation when teaching, but form part of programmes (e.g. all of these components are addressed in the morning ring).
Kinaesthetic learning	A learning style in which learning takes place by the child experiencing concepts using his or her body and senses.
Laterality	Developing awareness that the body has two sides (left and right).
Locomotor movement	Moving body from one place to another (crawling, walking, running, swimming, flying, sliding).
Non-locomotor movement	Moving on the spot, without going anywhere (twisting, bending, swaying, stretching, turning).
Midline crossing	The ability to efficiently move and use hands, feet and eyes on one side of the body in the space of the other side of the body, crossing the imaginary line that divides the body into a left and a right side.
Minimal support	The child is mostly independent, but needs support from time to time (e.g. can dress self, but needs support fastening buttons).

Multi-disciplinary approach	An approach in which more than one person is involved in assessing and planning interventions to support a child. It assumes that responsibility is shared among carers, teachers and parents/caregivers, and that a speech therapist, occupational therapist, physiotherapist and psychologist (and other relevant people) are involved when necessary.
Muscle contracture	The permanent tightening or shortening of a muscle that causes mobility limitations and joint stiffness.
Perceptual development	The ability to be aware of, perceive and make sense of the world.
Person-centred planning	An approach designed to assist someone to plan their life and support needs. It is used to enable people with disabilities to increase their self-determination and independence.
Proprioception	The sense of movement through space, where you are able to close your eyes and still be aware of the position of each body part and limb movements.
Responsive environment	An environment in which the child can obtain responses from other people and from seeing things happen as a result of what they do.
Sexuality	Incorporates characteristics of who a person is (gender) and includes biological, psychological, social and cultural components.
Shared exploration	Exploring activities with support (e.g. hand-over-hand feeding).
Spatial orientation	This defines the natural ability to maintain body orientation and/or posture in relation to the surrounding environment (physical space) at rest and during motion. Genetically speaking, humans are designed to maintain spatial orientation on the ground.
Structured free play	This is an approach to play where appropriate toys or objects are provided to children with disabilities, who then receive verbal and physical guidance/support throughout the play activity, and spontaneity is encouraged.
Supported participation	The child needs support to participate (e.g. supported seating and/or hand-over-hand support to enable participation in table activities).
Systematic instruction	This method of teaching new material includes presenting it in small steps and pausing to check learner understanding. It requires active and successful participation from all learners.

Transversal team	This refers to the transdisciplinary teams of health and education professionals needed to address the complex needs of children with disabilities.
Vestibular system	This is the sensory system in the inner ear responsible for providing the brain with information about motion, head position, and spatial orientation. It enables us to keep our balance, stabilise the head and body during movement, and maintain posture.
Visual-perceptual skills	Visual perception is the ability to see and interpret visual information in the environment. Visual-perceptual skills involve the ability to organise and interpret the information that is seen to give it meaning.

CHAPTER 1: Understanding disability

In this chapter we try to develop a better understanding of disability, and identify misunderstandings and unhelpful attitudes. We define what is meant by intellectual disability and show how to accurately describe severity levels by assessing intellectual and adaptive functioning. We explain how, by evaluating and describing children's conceptual, social and practical skills, we can better understand the severity level of disability and support needs.

We also look at issues affecting the inclusion of children with disabilities in society. We discuss the importance of a systems view of caring and educating children with disabilities, showing how relationships between children, families, the immediate and wider communities, and even international communities, affect the well-being of children and society as a whole. We also address the important role-players who implement policy related to children with disabilities and their right to education. Lastly, we consider your role in advocating for the rights of children with disabilities and the importance of early intervention.

When you have finished reading this chapter and completed the activities, you will be able to:

- Define the terms 'disability' and 'impairment'.
- Use the criteria for identifying potential intellectual disability.
- Understand the three domains of adaptive functioning: conceptual, social and practical.
- Differentiate between the severity levels of intellectual disability (mild to profound) by recognising the different functional characteristics displayed by children with disabilities.
- Discuss the importance of inclusion of children with disabilities in society and their associated rights.
- Understand the Circles of Care model in caring and educating children with disabilities.
- Identify the relevant role-players involved in implementing policy and taking responsibility for the care and education of children with disabilities.
- Reflect upon your role and actions in advocating for the rights of children with disabilities to education and adequate care.

1.1 What is disability?

Before we start working with children with PID, we need to look at our understanding of disability. Most of us are familiar with the medical model of disability, where people with disabilities are seen as having a bodily problem that needs a medical solution, and are therefore the 'responsibility' of health ministries and professionals. This is an 'individualising' way of thinking about disability. In other words, it sees the problems and challenges of people with disabilities as stemming entirely from their own bodily or functional differences. When we take this view, we take the person out of the context in which they live. The priority becomes the 'healing' of disabled people or, failing that, treating them as charity cases. This is not to say that people with disabilities don't need medical treatment. Everybody needs medical treatment when they are ill, and to live healthily, but it is not the *only* thing that is important about disability.

In contrast, the social model of disability was developed by people with disabilities and stresses the importance of looking at the environment in which people live and work. It also emphasises the need to change the environment to meet the needs of people with disabilities. For example, where there

are steps and no ramp, a person using a wheelchair is disabled by the steps and this is what needs to be changed, not the wheelchair.

The social model definitions of impairment and disability are:

Impairment The differences in the structure and functioning of body systems – the ‘medical diagnoses’ that people with disabilities carry.

Disability The loss or limitation of opportunities that prevent people with impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers.

For children with disabilities this means that their environment can be disabling or enabling, depending on their level of inclusion in family, learning and community groups. Disability is not just about people with impairments, but also how they interact with the environment and the support they receive.

According to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2007: 4): ‘Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’ In other words, disability is not only related to an individual’s limitations, but also to how much society adapts to their needs.

1.2 Defining intellectual disability

The Diagnostic and Statistical Manual of Mental Disorders (DSM–5) defines intellectual disability (or intellectual developmental disorder) as ‘a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains.’ (APA, 2013: 33)

Both parts of the definition must be considered when deciding whether a child has an intellectual disability.

Deficits in intellectual functioning These refer to difficulties in reasoning, problem solving, planning, abstract thinking, making judgments, academic learning and learning from experience, confirmed by both clinical assessment and individualised, standardised intelligence testing.

Deficits in adaptive functioning This means that the child has difficulty coping with day-to-day events in his or her environment, and is behind other children of the same age in terms of development, personal independence and social responsibility. These delays can limit functioning in one or more activities of daily living (e.g. communication, social participation, independent living), across multiple environments (e.g. home, school, work, in the community), if they do not receive the right kind of support.

Adaptive behaviour, which is learned and practised in daily life, includes conceptual, social and practical skills.

- Conceptual skills** Understanding abstract concepts of language, money, time, numbers, shapes, etc.
- Social skills** The ability to follow rules, observe social norms, and develop and demonstrate appropriate interpersonal skills.
- Practical skills** Carrying out personal care routines independently (e.g. dressing, practising personal hygiene and health care), demonstrating occupational skills, taking responsibility for personal safety, following routines, etc.

While you might think that people with intellectual disabilities are all similar, in fact there are notable differences that impact their ability to learn and in the support that is needed. DSM–5 is helpful in clarifying the levels of functioning of people with disabilities as it offers functional descriptions of the severity levels. It states that the level of severity is best understood by looking at functioning rather than IQ scores (APA, 2013). We can describe what a child with disability can and cannot do and, more importantly, what we can do to support the child.

1.2.1 Levels of disability

Although the focus of this manual is on children with PID, it is important to have an awareness of all the levels of disability (Figure 1).

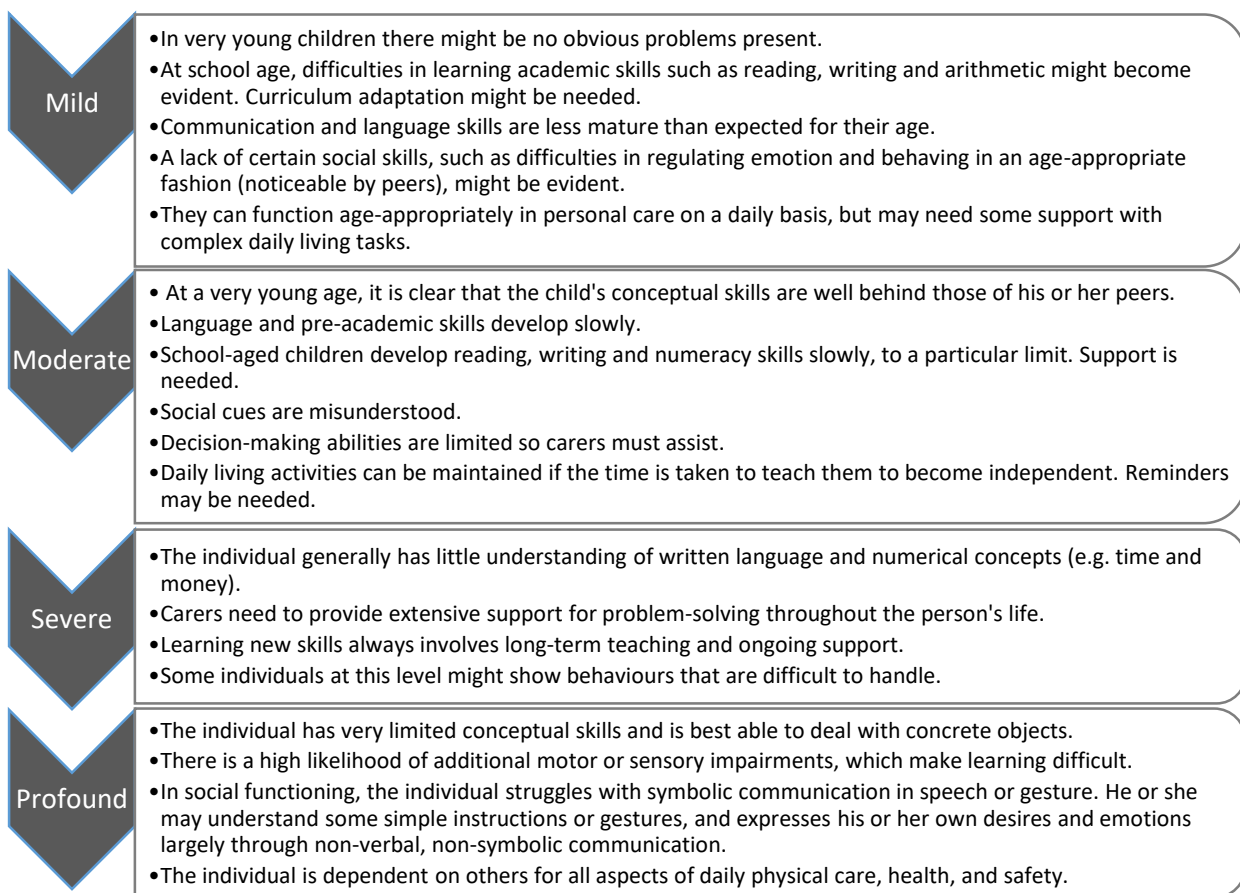


Figure 1: Disability severity levels.

As you continue engaging with this manual, you may find that some children/learners in your care/class do not fit the PID description and are better matched with the descriptors of other disability levels. You may then need to reconsider where they can get the best help and educational input, and whether it is appropriate for them to be following the PID curriculum. Some might do better working with the SID curriculum and there can be a degree of overlap between these levels.

Understanding PID

Children with PID have the same rights as anyone else and we need to ensure they are educated and treated with dignity at all times. To do this, we need to understand what being a child with PID means and what issues we might need to address to facilitate their full participation. DSM-5's description of PID offers guidelines, but it is important to recognise that no two children with PID are the same and that they will have different strengths and challenges.

Although we have chosen to focus on PID in this manual, there are grey areas between the different levels of severity. Children can sometimes move from one level to another, or may function at different levels in different domains. South African policy and research recognises this and refers to severe to profound intellectual disability (SPID). However, the concepts and activities in this manual focus on PID and may restrict the development of a child with SID. This approach is not intended to undermine the possibility of progress of children with SID, but rather to suggest that they will need different interventions at that level, which are not covered in this manual.

Within the *conceptual domain* of evaluating a child's adaptive functioning, children with PID have very limited conceptual skills and are best able to deal with concrete objects rather than symbols such as pictures or words. They may use objects for specific purposes in self-care, work and recreation (e.g. toothbrushes, toys). They can learn skills such as matching and sorting according to physical characteristics. There is a high likelihood of additional motor or sensory impairments, which make learning difficult.

In the *social domain*, children with PID struggle with symbolic communication in speech or gestures. They may understand some simple instructions or gestures, and may express their desires and emotions largely through non-verbal, non-symbolic communication. They enjoy relationships with well-known family members, carers and familiar others, and initiate and respond to social interactions 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 this happens.

Within the *practical domain*, children with PID depend on others for all aspects of daily physical care, health and safety. They may or may not be able to participate in some of these activities. Children with PID who do not have physical impairments may assist with simple chores around the home. With appropriate support, it is possible to engage children with PID in vocational tasks that depend on simple actions with objects, and recreational activities can be enjoyed such as listening to music, watching movies, going out for walks, or participating in water activities.

In summary, children with PID function at the lowest levels of adaptive functioning. They exhibit significant developmental delay and, although they can learn daily routines and aspects of self-care, they will always need a great deal of care and supervision. Multiple impairments including profound or severe motor disabilities, sensory disabilities, seizure disorders, chronic pulmonary infections and skeletal deformations are commonplace. In spite of these difficulties, it is important to understand that each child has the right to dignity and social participation.

1.3 Disability and inclusivity in society

1.3.1 Systemic thinking about children with SPID

In this manual, children with disabilities are kept at the centre of the discussion. They have relationships with others, including family members, carers (from different sectors such as education, social development, and health), the community, and the legislative policies of South Africa. The implementation of policies, attitudes from the community, intervention from carers, and family life all affect children with disabilities. They also influence how their families are organised, the role of carers in education, the responsibilities of the social and health departments, the participation of community members, and necessary policy revision. These inter-related relationships make up a dynamic circle of care and learning (Figure 2).

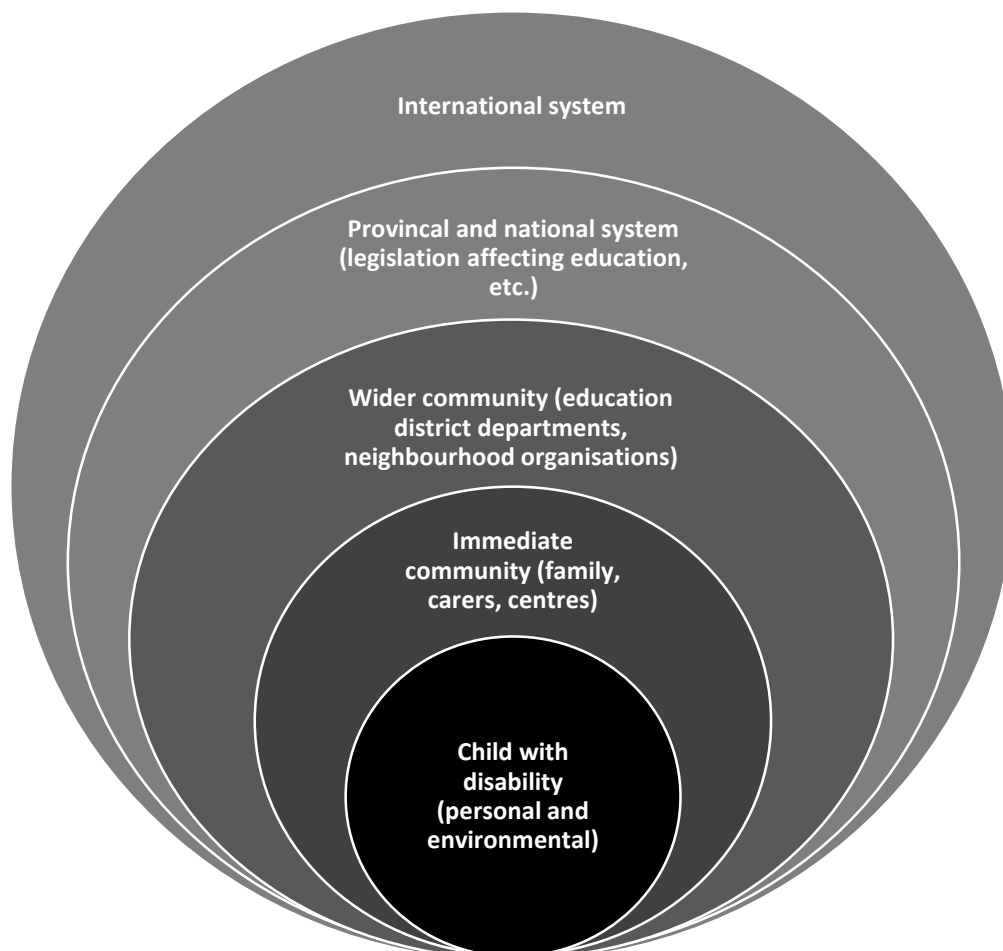


Figure 2: System levels related to educating children with PID. Adapted from McKenzie, et al. (2017).

Although each system has its own role, they also work together. This means that what happens at one level affects the other, which can be positive or negative. For example, a child with disability and his or her family can have a positive influence on their community by creating better awareness of the needs of vulnerable people. Similarly, if the attitudes of a community are negative, this can lead to isolation. The relationships between the child, family, community and wider society are key to achieving mutually beneficial outcomes.

1.3.2 Policy to promote inclusivity

Children with disabilities experience many barriers to participation in learning and are often excluded from social activities. The World Health Organisation's community-based rehabilitation guidelines (WHO, 2010) state that it is important for children's personal development to be included in social activities at the level of the family and local community. Participation in social activities has an impact on self-esteem, identity, social life and status. For inclusion to happen, people need to develop relationships with the child and see beyond the disability to the unique person inside.

The UNCRPD (UN, 2007), specifically Articles 10, 23, 24 and 26, describe the rights of children to:

- Receive education in an inclusive education system, close to their home.
- Have access to appropriate health services including assistive devices.
- Be integrated into family and community life.
- Be protected against cruel and inhumane treatment.

The UNCRPD also emphasises that all children must have the opportunity to develop their full potential, and have a sense of dignity and self-worth.



Activity 1A

We all tend to judge others, especially when they behave or look differently to us. Think about someone with a disability who has been judged either by you or by others, and has done better than expected.

1. Think about how different attitudes – judgmental or accepting – influenced the behaviour and abilities of the person with a disability.
2. What caused you or others to form this attitude?
3. What information changed your or others' point of view?

Guided by the UNCRPD, a White Paper on the Rights of Persons with Disabilities (WPRPD) was developed for South Africa (DSD, 2015). The White Paper aims to 'inform the promotion and protection of the rights of persons with disabilities in South Africa', and promotes a 'free and just society inclusive of all persons with disabilities as equal citizens' (DSD, 2015: 8). It highlights the need for disability equity at all levels of society and promotes awareness of the unique needs of persons with disabilities. There are nine strategic pillars to the WPRPD, of which Pillar Four is the most important in the education of children with disabilities.

Pillar Four's focus areas are:

- Early childhood development.
- Lifelong education and training.
- Strengthening recourse mechanisms (i.e. what do individuals and families do and where do they go if they do not receive the services to which they are entitled?).
- Supported decision-making.
- Access to lifestyle support.
- Social integration support.



Activity 1B

Read the descriptors for children with SPID in Figure 1. Then read about the focus areas of Pillar Four of the WPRPD. You may also want to consult the UNCRPD. Think about your answers to these questions:

1. Have you seen these focus areas lacking or present in the experiences of children with SPID?
2. What might it mean for children with SPID to have lifelong education and training, and access to resource mechanisms?
3. What might it mean for the families and caregivers of these children to get supported decision-making, and to have access to lifestyle and social support?
4. To what extent are these focus areas being realised by you and/or by those you care for?

1.3.3 Uncovering our assumptions and beliefs

Children with PID need to be loved and supported to reach their individual potential. They also need respect and connections with others as this is the way they learn. Children with PID have the same needs as children without disabilities.

Similarly, the families of children with PID have the same needs as any other family. However, the impact of caring for a child with disability places extra physical, financial and emotional stress on a family, including siblings and extended family members. Family support and community acceptance must be integral to any programme. It is also important to recognise that children with disabilities are valued by and make important contributions to their families.

The basic assumption underpinning our discussion and learning of how to care for children with PID is that all children can learn regardless of the presence and/or severity of disability. All children can learn depending on the instructional approach and support that is available. Children with disabilities need to participate meaningfully with others, and are not the only ones to benefit from such inclusion. Families, local communities and learning centre staff also benefit.



Activity 1C

Think about a child with a disability who you have a good relationship with and has enriched your life. Then write down your answers to these questions:

1. What aspects of your relationship with this child do you enjoy?
2. How does this relationship differ (or not) to other relationships you share with children without disabilities?
3. How does this relationship make you feel?
4. What do your feelings tell you about the unique relationship you have with this child?

1.3.4 The right of learners with PID to education

In South Africa, many children with disabilities have not had equal access to education and, in many cases, there is still not affordable and equal access. Some children with disabilities attend special schools but many others such as those with PID and multiple disabilities are not accepted into schools. Many stay at home and, in some cases, their guardians come together to form support groups and to create informal special care centres. While these types of informal care centres are exceptionally valuable, it also means that many children with PID are denied their right to formal education that is guaranteed by the Constitution.

In 2010, a group of non-governmental organisations, under the banner of the Western Cape Forum for Intellectual Disability (WCFID), won a court case against the national and provincial governments: *Western Cape Forum for Intellectual Disability v Government of the Republic of South Africa and Another*, 2011. In this case's final judgment, it was decided that: 'Every child in the Western Cape (and the rest of South Africa) who is severely and profoundly intellectually disabled must have affordable access to a basic education of an adequate quality.' The judgment confirmed that children with SPID have the right to basic education, protection from neglect or degradation, equality, and human dignity. The government was directed to:

- Ensure that every child with SPID has affordable access to basic education of an adequate quality.
- Provide adequate funds to organisations which provide education for children with SPID. This includes adequate facilities and staff.
- Provide appropriate transport.
- Enable staff of special care centres to receive proper accreditation, training and remuneration.
- Make provision for the training of persons to provide education for children with disabilities.

The DBE's draft policy for the provision of quality education and support for children with SPID 'recognises 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: 15).

In this manual we will look at ways to help make the right to education for children with SPID a reality. We know that children learn in different ways, so we will focus on how to educate and care for

children with disabilities, and how to create and provide the right learning environment to facilitate quality teaching and learning.



Activity 1D

Consider the actions of the people who challenged the national and provincial governments to make education for children with disabilities possible. Think about your and other people's attitudes towards education for children with disabilities. Then complete this task:

1. Design and make one or more posters for your centre/classroom that promotes care, education and positive attitudes towards rights for children with disabilities.
2. Share your poster ideas with other carers and centres.
3. Think about what you can learn from the actions of the people who initiated the court case. How can you become an advocate for the rights of children with disabilities at your care centre or school?

Remember that good posters have few words or a slogan, and attract attention using colour and simple images. You can write your own slogans or use any of these suggestions: 'Every child can learn', 'All children need love and acceptance', 'Working together for better learning and outcomes', 'Children with disabilities are lifelong learners', 'No child asked to be disabled'.

1.3.5 The need for early intervention

Children with disabilities have impairments that are often life-long, but they can develop or make progress over time with the right kind of help or intervention. The earlier this starts the better as it can support families at the same time, enhancing the child's development and reducing the risk of additional complications or disability. The intention of early intervention is to reduce the effects of the disability or delay, and to promote individual strengths and abilities.

The care received by children in their early years (from birth to five years) is primarily the responsibility of the Department of Health (DoH) and the Department of Social Development (DSD). In the near future, however, we can expect to see the DBE playing a greater role through early childhood education programmes and training. Departmental collaboration and early intervention in a child's life could make all the difference when it comes to continued learning in adult years.

In the next chapter we will focus on the centre of our care system: children with disabilities.

CHAPTER 2: Acknowledging and supporting children with disabilities

In this chapter we focus on understanding the needs of children with disabilities and the special considerations that the carers or teachers supporting them need to take. We explore what it means to get to know a child with PID and how you can do this sensitively and effectively to build a solid relationship on which to base valid assessments. We then look at what formal assessment of a child with PID involves, the assessment criteria, and other important factors that make up an effective, multi-disciplinary approach to assessment and intervention.

After learning how to understand the reasons for certain behaviours and the causes of stress for children with PID, we look at interventions that can be used to assist children to manage their emotions and achieve learning outcomes. We focus on learning how to communicate effectively and play constructively. We include practical ideas and topics to manage these processes on a daily basis, including how to choose activities and equipment for play, and ensure assistive devices are used effectively.

When you have finished reading this chapter and completed the activities, you will:

- Know how to get to know a child with PID.
- Understand what a multi-disciplinary approach to the assessment of a child with PID means.
- Know the criteria used to assess children within the focus areas of physical, cognitive and social development.
- Observe the behaviour of children with PID that indicates underlying frustration and other emotions.
- Be able to identify possible causes of stress and frustration for children with PID.
- Share ideas on how to manage particular behaviours and causes of stress often experienced by children with PID.
- Understand the role of play in the development of particular skills in childhood developmental areas.
- Know how to use and prepare play activities that achieve developmental and learning outcomes.
- Be aware of how to use assistive devices effectively to ensure optimal functioning.

2.1. Getting to know children with PID

Children with PID are among the most vulnerable, misunderstood and undervalued groups in our society. They are often judged for their silence, different movements and unusual ways of communicating. To find the potential of children behind outward appearances, we have to foster our ability to engage and support them. In this way, we will learn how to unfold the learning process in each child with PID.

Determining the abilities and severity levels of children's disabilities takes time and thought, and requires contributions from different team members. However, once a child is understood through thorough engagement and assessment, a solid foundation is laid for the necessary care and learning interventions. Over time, a child with PID will grow and develop with the help of the right interventions, demonstrating that comprehensive assessment initiates and develops into an ongoing and lifelong-learning process.

The child with PID may have multiple and complex impairments, including health risks such as seizures, contractures and deformities, feeding and chest conditions. It is therefore important that children with PID are assessed in domains such as their physical, social and conceptual understanding abilities.

2.1.1 Initial engagement

We can sometimes forget that we need to get to know children with PID in a similar way to children without disabilities. It is important to give children with PID the same respect and courtesy. When you first meet someone, you might ask, 'How are you?' and then perhaps, 'Where were you born and where did you grow up?' Getting to know children with PID follows a similar format, starting with background information and then going deeper to find out what interests and motivates them to interact with the environment and people. Getting to know someone takes time as there are many different aspects and layers to a person's personality and life experiences.

The introductory questions and topics below may be helpful in building rapport with the children in your care. Depending on the severity and type of disability, it is likely that the questions cannot be answered directly by the child and you will need to engage with the child together with his or her parent/caregiver to find out the information.

- Where and when was the child born?
- Where does the child live?
- What family does the child have? How does the child get on with other family members/siblings?
- What experiences has the child had with previous care/interventions/school placements, etc.?
- What are the child's interests (i.e. hobbies, topics of interest, favourite pastime)?
- What motivates the child to play and engage with others and the environment?

2.2. Assessing children with PID

The best way to assess children with PID is by observing their abilities and skills within the physical, cognitive and social areas of development. Observing children within these domains will give you an idea of their abilities and potential. What you observe will change over time as children grow and develop, and it is important to record these developments. Developing your observation skills as a carer can take many years of practice. We often observe children through our own particular personal or professional lens and only see certain aspects of their behaviour or development. This is why assessment should be done in a group with other carers, including family members.

It is one thing to observe, and another to reflect or think while we are observing. Making observation notes and compiling a written assessment is one way to ensure that we reflect and consider carefully what has been observed. Often there are links between different observations made by different people, which can help us to understand the child more holistically and make more sense of why he or she acts and behaves in particular ways in similar or different contexts. It is often necessary, and recommended, to repeat observations of the child and evaluate the same specific aspect of his or her behaviour to ensure reliable information is recorded.

2.2.1 A multi-disciplinary approach to assessment

The focus of any assessment must be on what the child can do and the things the child can nearly do (potential). It is also worthwhile observing what prevents the child from doing what he or she can do in a better way, or what interferes with a child reaching his or her potential.

Questions to guide and underpin your observations include:

- What can the child nearly do in terms of physical, cognitive and social skills, demonstrated through what the child moves, understands, says, interacts with, etc.?
- What can the child do with support in these areas?
- What does the child do when not under pressure (e.g. during free/unstructured play?) Observe how the child plays without interference from others.
- What is the child able to do at home that is not always seen at the school or centre? In other words, what does the child do when he or she feels safe and comfortable?

There is a potential to develop in every child. At times, children with disabilities are not expected to do anything for themselves and so they don't. This can develop into 'learned helplessness'. It is important that you differentiate between what children are not able to do, what they are not able to do with support, and what they are not willing to do. This will help you to unlock potential and determine the child's real rather than perceived abilities. The differences between real and perceived abilities often stem from the environment in which they are observed and who is observing them. Children may be able to perform differently – often more confidently and showing more prowess – when they are in a familiar environment with people they are comfortable with such as their family members. The family is an essential part of the assessment process. Carers getting to know and assessing a child with PID also have to get to know and understand the child's family.

Children have different relationships with family members, school peers and facilitators. There may be a particularly close bond with a primary carer who can interpret communication gestures such as sounds and facial expressions. The family may also be able to indicate what the child enjoys and motivates laughter, play and interaction. This information is vital to any comprehensive assessment. A child and family focused assessment approach leads to a more accurate assessment and effective interventions being put in place. This results in better outcomes for the child and the family.

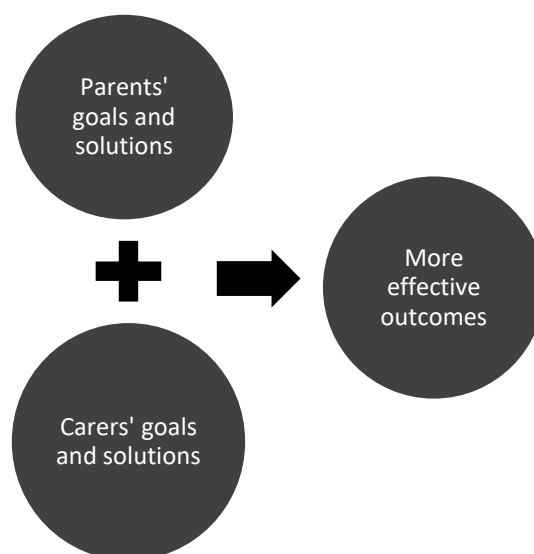


Figure 3: A combined approach to assessment.

By following this approach, any potential gaps between the observations of carers during a formal assessment at a centre and the experiences of family members at home can be closed. A fuller story of the child can be reached by considering all the perspectives and observations of carers and family members. With this combined, clearer understanding, everyone is involved in creating and working towards shared goals in the assessment and subsequent interventions. This is described as a multi-disciplinary approach to the assessment and care of children with PID, which assumes that responsibility is shared with the carer, teacher and parent/caregiver, and that medical and other specialists are involved as and when necessary.

Involving the family in assessments

Within the network of social systems referred to in Chapter 1, children with PID can be:

- Active – participating in immediate and wider systems such as the family, school and community.
- Passive – present but not participating, or
- Separate – isolated from the family and other social circles.

It is important to gather information about how the child interacts with these systems, which makes the involvement of family members in assessments vital. Here are some suggestions for doing this successfully:

- Give family members and other carers the opportunity to describe the child from their own viewpoint in the contexts in which they see the child the most (e.g. at home or school).
- Encourage family members to tell stories their relationship and experiences with the child.
- Ask the family questions about:
 - The physical environment in which the child lives or plays: Is the home and the area outside the home accessible to the child?
 - How the child socially relates to other people in the close community: Are your neighbours aware of the child? Does the child attend a care centre or belong to a social group such as a church, or play or care group? Describe the attitudes of people in your extended family, community or social circles towards your child. How does this affect you?
 - The support available to the family: Who helps you care for your child or with other aspects of family life? Does the family participate in community events?
 - Family goals and aspirations: What are the family's goals for the child both now and in the long term? What are some of the family's concerns for the future? How does the family plan to solve some of these concerns? What information would be helpful to manage this?



Activity 2A

Ask a family you work with to tell you a story about their child that highlights their hopes and expectations, any discouragements, and plans for progress. Listen carefully, practicing non-judgement, and then share your experience of the child. Afterwards, reflect on these questions:

1. How does the family's description help you to understand the child's role in the family?
2. How is their story similar or different to yours?
3. How does another view of the child help you to know the child better?

2.2.2 Assessment focus areas

The assessment or observation of a child with PID should focus on the child as a whole and take into consideration the different developmental stages. The criteria or aspects observed during an assessment should be used to monitor a child's progress over time. The areas for assessment recommended below are aligned with the International Classification of Functioning, Disability and Health (ICF) used by the DoH and the DBE.

Focus area	Skills/functions	Observation questions
Physical development	<ul style="list-style-type: none"> • Use of senses (vision, hearing etc.) • General health condition • Muscle and joint strength • Range of motion/flexibility • Co-ordination • Bodily functions (e.g. breathing) • Life skills (e.g. self-care, eating habits) 	<ul style="list-style-type: none"> • How does the child use his or her body? What does the child always do? How does the child move? • How does the child eat, drink, dress and wash? • What can the child's hands do and how?
Cognitive development	<ul style="list-style-type: none"> • Learning ability • Planning movement • Memory • Attention/concentration • Ability in play • Visual perception 	<ul style="list-style-type: none"> • What does the child choose most often to play with? • How does the child play? What interferes with how the child plays? • If the child's vision is involved, how does the child see and adapt to playing? How do the eyes and hands work together?
Social development	<ul style="list-style-type: none"> • Communication skills • Interpersonal skills (e.g. interaction with others, participation in activities) • Socialisation skills 	<ul style="list-style-type: none"> • How does the child communicate his or her needs? • What does the child understand? • How does the child interact with others?

The three areas of learning development also align with the learning programme outlined in the DBE's curricula for children with SPID. Although slightly varying terminology may be used by the different departments, these areas of development are the focus areas for any assessment or intervention planning. Other organisations may use different words to describe various aspects of childhood development which also can be used to guide observations and assessments. For example, specific points to look out for during assessments are categorised in appendices A and B under the headings 'physical development' and 'mental and social development'.



Activity 2B

CanChild is a Canadian programme that uses 'F-words' to describe the six areas of child development: Fitness (health condition), Function (activity), Friends (participation), Family (environment), Fun (personal), and Future.

1. Watch the videos and/or read the articles on CanChild's website that tell you more about 'F-words', which help describe the focus areas of childhood disability.
<https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability>
2. Note down any words or terminology you have not heard of before and discuss these with someone who can help you to understand them.

Physical and cognitive development considerations

Some parents/caregivers are given a medical term or explanation for their child's disability by a medical professional. For many children, however, a specific diagnosis may not be made and a general term such as 'global development delay' is used to describe their condition. This simply means that there is a delay in all the focus areas of the child's development.

Only qualified medical professionals, such as doctors, can make a definitive diagnosis, but it is important that carers understand the condition and its implications. To understand more about a child's physical health, you can ask the child's medical practitioners or family members these questions:

- What is the diagnosis, reason or words used to describe the child's disability(ies)? What does this diagnosis mean in simple terms?
- Is there a single diagnosis, or more than one, such as cerebral palsy and visual impairment or epilepsy?
- What do you know about this diagnosis and what would you like me to know?
- How does this diagnosis affect the child's abilities and functioning?
- Do you know of another child with the same diagnosis?
- What medication is the child using? How does this help the child to function better?

When asking family members about the child's history (e.g. the child's birth and prenatal care), do not ask questions that sound judgmental or infer blame such as, 'What did you do during your pregnancy that could have caused a disabled child?' This is not only insensitive, but can also be misinformed. Rather ask medical practitioners about the causes of certain disabilities.

Childhood development follows a sequence or progression. Children learn and adapt to their surroundings according to their abilities and/or skills. For example, a new-born baby moves randomly and is calmed by his or her mother's voice, but does not actually see or recognise her facial features. After a few weeks, the baby is able to recognise the mother's face and respond to it. The baby learns and acquires one skill after the other until he or she reaches a developmental milestone such as smiling. Developmental milestones refer to the big skills children acquire such as smiling, rolling, sitting and walking, after having learned smaller skills such as recognising sounds and sights. There

is an expected timeframe for the acquisition of developmental milestones. For children with disabilities, these timeframes vary because they have to overcome many barriers and challenges to learning new skills. Any physical or cognitive impairment makes learning skills much harder for children. Often the first sign of an impairment only becomes apparent when children do not reach developmental milestones successfully within the average timeframe. When developmental delays are reported to medical professionals, an early diagnosis can be made and interventions put in place to achieve better outcomes for the children and their families.

Social development considerations

There are many reasons why people behave in particular ways. Our behaviour and actions show our thoughts and feelings. If a child is hungry, the action used to communicate this need could be pointing or looking at the food, or moving towards where the food is kept. Observing a child's behaviour is to try to understand the need and how the child is trying to communicate this. Children with disabilities may communicate their needs in different ways that require carers to interpret and understand carefully. They often have difficulty with verbal communication and may use physical movements and behaviours instead of words to communicate. Mouth pouting or dropped lips, smiles, looking in a direction, turning away, closing eyes and blinking may be some of the behavioural signs that communicate the needs of a child with PID. If these needs are not met, the child has a few choices: to become louder or quieter until there is a response. Becoming louder might mean that they demonstrate disruptive or difficult behaviour to communicate their needs. Becoming quieter might mean that they give up on saying what they need. Neither response is helpful to their continuing development.

Getting to know children with PID will help you to pick up on their communication patterns and learn their 'substitute language'. Knowing and being able to read these signs will enable you to assess children and intervene more successfully.



Activity 2C

This case study is about Sam and how he was assessed. It highlights how the assessment and intervention programme is reviewed and changed to meet Sam's changing needs as he grows and develops. Read Sam's story and then write down your answers to the questions in a notebook.

Sam's story

Sam is a five-year-old boy who has been at your centre for a few months. He lives with his father, pregnant mother and older sister who is in Grade 1. His mother works and his father is unemployed, but helps in the community with small building and vegetable garden projects. They live in a two-roomed house in a small neighbourhood. Sam is a happy boy and smiles when he is held and played with by familiar people. He attends a care centre during the day. Sam receives a Care Dependency Grant, which helps to pay for his school fees.

The mother's pregnancy with Sam developed normally. Similarly, Sam developed normally in his first few months. At five months, Sam got ill with TB meningitis and nearly died. As a result of this illness, Sam was diagnosed with cerebral palsy, and has

suffered vision and hearing loss. He eats well and loves soft porridge. His parents have to feed, dress and wash him. Sam has seizures that are mostly controlled with medication.

Assessment questions	Physical development	Cognitive development	Social development
What can Sam do by himself?	Hears loud sounds Looks at toys close to eyes Turns head to look Eats porridge and soft food Drinks yoghurt and sips water Wears nappies Moves hands and arms Legs don't move much Tries to reach for object with left hand Lies on tummy if placed Sits in a chair if placed Cannot roll over	Looks at people when they are close to him	Laughs and smiles when hears singing Knows his father's voice Makes some noises to get attention Cries when left alone
What is the easiest movement/function for the child?	Lying on his back and playing or listening to music		Smiling
What is difficult for the child to do?	Sitting and using hands to play	Responding to visual input	Communicating needs
What does the child want to do? <i>or</i> What motivates the child?	Loves to hear singing and feels the rhythm of music	Loves food Sees a little	Smiles at family
Circle or mark the abilities of the child where you can begin a programme	<i>Use Appendix A or a similar chart to do this</i>	<i>Use Appendix C or a similar chart to do this</i>	<i>Use Appendix B or a similar chart to do this.</i>
Draw a symbol or picture to represent the child's ability	<i>If charts do not adequately describe the level of the child's ability, draw diagrams to illustrate this.</i>		

1. How do assessment notes help you, as a carer, to plan interventions for Sam?
2. How do assessment notes show that the family was included in the overall assessment?
3. What is helpful about using charts (e.g. appendices A and B) and diagrams in an assessment?

2.3 Communicating with children with PID

2.3.1 What is communication?

Communication is used to exchange information, ideas, needs and desires. It is a two-way process that involves understanding others and expressing ourselves. It also requires skills that can be taught and learned over time. Children with PID often have speech and language challenges, but if we change the way we communicate and the tools or strategies we use with them, we can provide options to communicate more effectively. These are some of the ways in which people communicate:

- Speaking words and making sounds.
- Using body language such as gestures (pointing, waving, etc.).
- Using facial expressions (frowning, smiling, rolling our eyes, etc.).
- Making eye contact or gazing.
- Using symbols and pictures/photos.
- Through reading and writing.
- Using sign language.
- Touching things.
- Singing and dancing.

We all have a need to communicate, regardless of our ability to do so effectively. We therefore need to look for practical tools to help children with PID communicate in ways that suit them best, which may not be verbal communication. We have to adopt a functional communication approach that values practical ways of exchanging information. With an increased ability to communicate effectively, children with PID will also:

- Gain increased independence in self-help skills because they are able to communicate their choices during activities such as feeding, bathing, dressing, etc.
- Gain more awareness of themselves and others as communication partners.
- Learn what is socially appropriate when communicating with different people.
- Develop closer relationships with people in their community, increasing their sense of belonging.

Communication skills are continually developed from simple to more complex skills using a variety of activities. Basic communication skills that children should practise and develop are:

- Listening to the sounds of communication and making a response.
- Making sense of the sounds in words and finding own sounds or words to respond.
- Listening to the words in sentences with understanding and making a response (e.g. 'Would you like some water?' elicits a nod response.)

In learning to communicate with children with PID in such a way that both you and the child can understand, consider some of these starting points:

- Observe how a child communicates his or her needs.
- Be attentive to how a child communicates and respond with affirmation.
- A child may attract attention by shouting or making loud noises to express something negative. Introduce various positive ways to communicate needs such as nodding to indicate 'yes' and shaking the head for negative responses.
- Introduce choice in your interactions. Let them show you what they would like to have/do/eat, etc. as this promotes the development of decision-making skills and increased autonomy to direct themselves. The promotion of self-direction or self-determination is helpful in encouraging children with disabilities to exert control over their lives and become independent.
- Use augmentative and alternative communication (AAC) strategies to create choice and decision-making opportunities.
- Allow pauses and 'more time than usual' for children to respond.
- Where possible, allow children to use body language and other non-verbal ways of communicating to replace speech.

Assisted choice making

It is important to identify how the child communicates and how you can further develop this. Every child is at a different level in terms of identifying communication signs. Find an item (e.g. a real mug, a photo of a mug, a picture of a mug, or just a line drawing of it) and ask the child a short, simple, easy to understand question about which one they want: 'Which one?' or 'Do you like this?' It also helps to keep the objects close enough for them to see, but a distance apart so they can see the differences between the two. Notice everything the child is doing and wait for a response. Some children respond by:

- Looking in the direction of the object.
- Smiling at the object or frowning at an unwanted object.
- Making a sound or vocalisations, trying to say which one they want.
- Pointing or reaching towards the item.
- Giving a nod or head tilt towards the item.

As the communication partner, you will also need to model or request a specific response from the child. Look and listen carefully to identify how the child is responding or making choices. You could also provide assisted choice making by using your hand over the child's hand, or making a choice for them and seeing if they agree with it.

Augmentative and alternative communication (AAC)

When using AAC with children with SPID it is important that the communication tools and strategies are best suited for each child. What is useful is creating a personal communication book in which you make a list of important words and actions that the child will need to know or use daily in their different environments to express their needs and wants. Various online guides are available for creating visual schedules and activity choice boards. Visual schedules or guides can also be used for self-care activities and to express feelings. These tools can be used by children not only to communicate with carers and teachers, but also to communicate with friends and peers at school.

Communication books can be made as table boards, digital apps, photograph books, ring-bound flip booklets or even posters.

Behaviour as communication

There are reasons for most behaviours and expressions of emotions shown by children with PID. Children may express their emotions through behaviour that is shy, aggressive, happy, sad, irritable, or results in shouting, helping others, etc. Identifying possible reasons for such behaviours is helpful in understanding children with PID and how to help them more effectively. Here is an example:

Behaviour	Possible reasons for behaviour	Positive and negative influences on others	What can be learned?
Smiling – looks happy	Loves food and snack time Enjoys social contact during meals Has just eaten	Makes others happy Children move closer to happy learner Quieter environment	Create more ‘happy’ moments in group situations Use the happy learner to influence others

We all have times when we experience some sort of stress – often because what we want or feel is not recognised or realised. This is no different for a child with PID, who also has unmet desires that cause frustration. Learning how to recognise signs of frustration or stress in children with PID will help you to identify possible reasons for certain behaviours. Skills for managing stress and frustration being experienced by children with PID include:

- Observing for non-verbal signs of frustration (e.g. frowning, lips turned down, rigid body).
- Attempting to identify the stressor by being aware of what is going on in the environment (e.g. excessive or repetitive noise).
- Naming the stress and talking about it (e.g. ‘That was a loud noise. You got a fright.’ or ‘That was a big truck going down the road.’).
- Reassuring the learner (e.g. ‘The truck has gone.’).
- Giving the learner a coping strategy (e.g. ‘When you hear a loud noise, cover your ears and take a deep breath.’).



Activity 2D

Read Sandra’s story about her experience with a boy with PID. Think about this case study and what you can learn from it, then answer the questions and complete the tasks.

Sandra’s story

I have a boy in my class called Zac and he is very busy. He can’t sit still for long – he has two spoons of food and then runs away. I have tried to teach him to hold a spoon, without any success. I noticed, though, that when I gave him play dough, he held it the whole day and was quiet and calm.

So the other day I gave him a piece of play dough in the morning. At lunch time I asked him for the play dough and he gave it to me. I left it on the table so that he could hold a spoon to eat. Zac has been learning to eat by himself. By keeping the play dough on the table, he knows that after eating he will get it back again. Play dough doesn't work for every child, but it did for Zac.

I think he trusts me because I respect his needs and will give him the play dough when he needs it. The play dough stays in the classroom when he plays outside.

1. Did Zac's behaviour and learning improve through using play dough or because of his relationship with his carer, Sandra?
2. Zac could not concentrate on anything for a long time, even during meals. Short attention span, restlessness, irritability, hurting self and others, stressed, anxious, tearful, quiet, shy or aggressive behaviour, and shouting are possible behaviours you have seen. Write down reasons and possible solutions for these behaviours.
3. Observe the behaviour of children in your care. Are there any patterns?
4. Make a poster for your workplace that describes the observed causes of stress for the children in your care, along with actions they or you could take to help alleviate the stress (e.g. 'When I feel worried, I take a deep breath.'). You could use symbols or pictures to represent the support options such as deep-breathing or stretching. This poster can be used to remind parents how they can emotionally support their child.

2.4. Playing constructively with children with PID

People are inwardly motivated to play, and it is through play that we learn about ourselves, the environment and make connections with others. Children learn how their bodies move, what objects can do, and how to interact with others through play. Play and having fun is a 'language' of all children, no matter their ability.

Play should be seen as a lifelong activity or occupation. Children play with simple ideas or games, which then develop into play for adults (sport, hobbies, music, reading, etc.) which may last a lifetime. Having fun and playing is essential for well-being. People who do not play are often more stressed than those who do. The United Nations Convention on the Rights of the Child (UNCRC) Article 31 (1990) states that every child has a right to play, which indicates the importance of play and that it should be included in all aspects of a child's life.

2.4.1. The role and value of play

Play fulfils many roles. Among its benefits, it:

- Encourages the learning and development of social and emotional skills and abilities such as patience, self-discipline and tolerance of others.
- Helps children learn how to 'lose', and to make and use mistakes constructively.
- Aids cognitive development by involving processes and steps such as following instructions, problem solving, etc.
- Affirms for children that they are 'good enough' and celebrates their successes.
- Teaches children how to give and receive, or take turns (reciprocal play).

- Assists children to understand social cues such as non-verbal signs of emotions and facial expressions.
- Teaches children about social expectations and culture such as copying adults' behaviour when greeting others.
- Teaches children how to interact with their physical environment and the physical objects in it.
- Connects different generations, especially through music, song, storytelling, etc.

The process of play is more important than the method or outcomes. What children learn through play is extensive, and whether they are 'winners' or 'losers' is often irrelevant.



Activity 2E

Children learn through the process of play and by making mistakes. Read Joseph's story and think about your answers to the questions that follow.

Joseph's story

Joseph is a three-year-old boy, the youngest of three children in the family. He was born premature and developed a brain haemorrhage (bleeding) that led to cerebral palsy. Joseph loves to push himself backwards and push himself on his back on the floor. He knows that his family doesn't want him to get hurt, and has learned that if he pushes himself backwards, family members will rush to him and keep him safe from falling. Joseph enjoys this fun game, but the family don't. Joseph smiles while everyone else breathes a sigh of relief when he doesn't hurt himself.

1. How often and in what ways do you encourage the children you care for to play.
2. What is your intention when encouraging play – to encourage participation or to move them towards results?
3. How could you focus more on the process of the child's participation in play, rather than the result or what he or she did?

Social development through play

As with other aspects of child development, social abilities advance in a sequence, from simple playing alone, to observing and copying play, to playing alongside others, to following social norms in play. Educational theorist, Jean Piaget, described children's cognitive development through four stages (Louw, 1998):

- **Sensorimotor** (0–2 years): This is a stage of rapid development. Children acquire knowledge through sensory experiences and manipulating objects, and relate to the world through basic reflexes, senses, and motor responses. They also learn a great deal about language during this stage.
- **Preoperational** (2–7 years): The emergence of language is one of the biggest milestones of this stage. Children become much more skilled at pretend play, but think concretely about the world around them. They struggle with logic and the points of view of other people.

- **Concrete operational** (7–11 years): Although thinking is still very literal, children start to think more logically, but still rigidly. They become more mindful of other people and their perspectives, but still struggle to understand abstract and hypothetical concepts.
- **Formal operational** (11– 20 years): In this stage, children have an increase in logic, the ability to use deductive reasoning, and an understanding of abstract ideas. They are able to see multiple solutions to problems, and to think more scientifically about the world around them.

Play facilitates not only these stages of cognitive development, but also social development. Learning social skills such as advocating for self, decision making, working in groups, and sharing and resolving conflicts, are as important as the cognitive skills that play develops. Children learn to communicate through meaningful social interaction. They copy adults' behaviour to learn about socialising and relating to others. It is also through play that children learn and develop as individuals: it assists in their emotional and intellectual development, mental health, and resilience, which are core building blocks for their transition years.

As children with disabilities develop into adolescents they may learn about their bodies in a more sensual way, which is age-appropriate and should be understood. The body of an adolescent may develop and be influenced by hormones. Carers need to be sensitive to this and respect the changes and the person's privacy, while helping him or her to know what is appropriate and what is not.

2.4.2 Special considerations in play with children with PID

Parents can be the best source of knowing what and how a child with disability prefers to play. This is mostly based on the time shared between parent and child, and the parent noticing what the child enjoys. This indicates that relationship is central to good play.

To truly engage in play with a child with disability is challenging. Often you may feel fearful of not knowing what or how to play with children with disabilities appropriately. All children love to play and finding the appropriate game may take longer for children with limited functioning. Each child engages and plays differently, and may have limited ability to participate in certain play activities. It is therefore recommended that you first spend time observing how specific children open up during play, show interest in different games/activities, and what meaning different children attribute and gain from particular activities (e.g. different reactions and understanding of a game of peek-a-boo).

The skills and abilities of each child in the different developmental areas will determine how a child with disability plays. However, at the same time, play enables children with disabilities to learn varied physical, cognitive and social skills. Unstructured, free and loosely supervised play should be encouraged as much as possible to allow children to initiate and explore through play. At times, too much structure or over-programming spoils the true benefits of play.

The roles of carers and children in play

Much of play is spontaneous and just happens when there is a playful attitude. The success or learning potential of play is largely dependent on the carer's ability to:

- Recognise the potential of the play activity.
- Follow the child's lead.
- Trust his or her skills to follow the process, which may mean that the initial aims are put on hold (to be continued at a later stage).

Playing with a child offers insight into what the child is able to do, and reveals motivations for learning and engaging in life.

Giving instructions for play activities

Ensuring that you achieve the outcomes of the play activity you have planned often depends on how clear your instructions or directions are. These guidelines may help you to frame play activities with children with PID:

- Start with an activity that the child can do fairly easily to boost their confidence.
- Be patient and allow extra time for the child to understand and process information.
- Give clear instructions, one step at a time. These instructions need to follow a sequence that makes sense to the child.
- Keep instructions clear and simple.
- The instructions may need to be direct (e.g. Hold the box', 'Pick up the toy', 'Put the toy in the box').
- Repeat the instructions. You may need to repeat the instructions several times in different ways.

Choosing equipment for play activities

Toys and activities should be chosen according to the child's specific abilities, skills and interests, and be age-appropriate. For example, a ten-year-old who can only hold and shake a toy should rather be given a musical instrument than a baby's rattle. When choosing a toy or activity, consider:

- What the child can do (not what he or she cannot do).
- The learning goals for the child in his or her developmental areas.
- The properties of the toy. For example:
 - Safety – Does the toy have sharp edges, or is it so hard or heavy that it could cause injury?
 - Adaptability – How can the toy be adapted to match the child's abilities? Some adapted toys are available, but they are often difficult to find and expensive. Although many toys rely on technology, with some thought, low-cost adapted toys could be made.
 - Motivational value – Simple toys are often the best as they teach certain skills but have high excitement or interest value, resulting in implicit learning (e.g. balls that make a sound when rolled teach cause and effect).



Activity 2F

1. Observe a child in your care who has partial hand function. What does the child can do with his or her hands?
2. What activity could this child do with his or her hands?
3. Make an adapted toy using materials that are readily available (e.g. recyclable materials) to help the child use his or her hands.
4. What would the aim of the toy be?
5. How can the toy be adapted for other children with different needs and in different contexts?

Tips for play activities

- Be spontaneous and free in playing with children. How you start the activity may not be how you end it. Enable maximum participation physically, cognitively and socially.
- Facilitate the child's interest and motivation to play.
- Concentrate on the play process rather than the end-product.
- Ignite a child's interest at the start of the activity to improve active participation and enjoyment.
- Maintain a sense that the child has mastery during play. In other words, keep activities at a level where the child can adequately complete the required tasks. This builds the child's confidence for later play and learning activities.
- Use play rather than toys as a motivator. Toys are simply tools for play, but playing without toys is also a skill to be learned and fostered.

Warnings about play activities

- Avoid using a toy that requires manipulation while the child is in a difficult physical position that requires balance.
- A child should be well supported when exploring a toy that requires finger movements.
- Don't repeat the same activity over and over again (e.g. using a puzzle that a child has just completed). Make small changes in the activity so that the child remains motivated, or use a similar activity such as a different puzzle.
- Do not remove or place a toy further away from a child when he or she reaches for it. A child may stop reaching for a toy if there is no motivation or reward for doing so.



Activity 2G

Reflect on your ideas about children with PID, and the benefits and role of play in their learning. Complete the activity below and discuss your observations with other carers.

1. Choose a child in your care who enjoys playing. Play *with* the child using an unstructured, unplanned, free-play approach. Follow the child's lead, then add something to the play activity and notice the child's response. Consider the child's response as you progress the activity.
2. What does the child bring to the play activity?
3. In what ways can carers play *with* a child instead of playing *for* a child?
4. Discuss in a group how to link different skills in children's developmental areas with play activities (e.g. the social skill of waiting for a turn to roll a ball in a group activity).

2.4.3. Physical activity and play

All children need to be active and fit enough to participate and function in life. This is no different for children with disabilities, who often do not get enough experience and practice of movement and physical activity. A child with disability needs to move as much as is possible for his or her well-being and to maintain muscle flexibility. Children with disabilities learn how to move through exercising, which assists with functional movement and may support independence.

Promoting physical activity through play

- All movement is good and children find out what their bodies can do through moving randomly without risk of failure. Encourage children with PID to explore movement and what their bodies can do. Children with disabilities who do this from a young age may have greater potential to move functionally (e.g. the ability to sit and stand).
- Lack of movement can lead to stiffness. Gentle massage in a safe, warm space can be a relaxing and enjoyable experience.
- Encourage children to use different positions for movement such as lying on their backs, lying on their stomachs, side-lying, supported sitting, etc.
- In each position, help the child to use different body postures (e.g. side-lying with arms up or down, legs straight or bent, open or closed). Each limb can be placed in a variety of positions.
- Support and encourage the child to move in and through different positions during play activities.

2.4.4 Grading abilities and activities

Choosing an appropriate toy, game or activity for a child with disability can be challenging. This can be made easier if there is a good understanding of the child's abilities and skills. Good interaction through play implies that the activity is neither too difficult nor too easy and the child stays motivated during the activity.

Grading an activity involves adjusting or changing an activity so that it requires a higher level of skill/ability from the child, thereby facilitating the learning of new skills. For example, you could grade the activity of rolling a ball on a table to a more difficult task such as standing instead of supported sitting while rolling the ball. Grade one activity at a time to enable the child to master a particular functional activity. General principles for grading are:

- Start by finding an activity or game that is well suited to the child. Ensure that the child's abilities match the demands of the activity.
- Experiment with what works best for the child.
- Don't be afraid to try different ideas for play.
- Observe responses carefully: Is the child engaged in the activity? What tasks involved the child in the activity? How could you increase the child's engagement?
- Grading must be an ongoing practice as children tend to repeat what they can do best. It is important that children work on their weaker areas to achieve overall strength in the different developmental areas.

Another consideration is ensuring that expectations are not set too high or too low. If children think they can do more than they are actually capable of, anxiety and disappointment are likely when they are unable to complete a task. Similarly, if children cannot complete a task that they thought they would not be able to, this often leads to them becoming passive and disinterested. A simple activity that encourages children's involvement and learning is better than a complex activity that results in children watching passively. Results can reinforce children's beliefs in their disabilities, so it is important to focus on abilities and what they *can* do.

2.5 Working with assistive devices

Each child has individual abilities and needs and therefore has individual requirements for support, including assistive devices. Assistive devices are designed to help children perform functional activities more successfully (e.g. walking with a walking frame). Essentially, assistive devices should enable children to function optimally so that they can interact with their environment and others more easily and effectively.

It is important to remember this: Carers must check that assistive devices are properly fitted and performing the function they aim to support. If they do not fit well and are unsuitable for the child, they can limit what children do and their progress in the physical, cognitive and social developmental areas. There are many different types of assistive devices and designs keep advancing to better meet children's needs. Therapists should keep up-to-date with the latest assistive devices available so that the best options are chosen to support children most effectively. Therapists can help you to make adjustments to assistive devices to maximise their support.

Choosing a device can be quite technical, so it is always better to plan and evaluate its use with experienced colleagues. If children have to share assistive devices in a classroom or at a centre, a carefully planned roster needs to be designed so that each child has adequate time using the device and benefits from the support.



Figure 4: Choosing an assistive device is based on individual needs.



Activity 2H

Children with PID need to use assistive devices to experiment with different positions and movements throughout the day. They should not be in one position for longer than 45 minutes.

1. Draw up a roster for the group of children you care for so that each child has a chance each day to use the assistive devices available to you.
2. Write a timetable for your daily programme with the different positions of each child, and who uses what and when.
3. Ask a colleague if you can observe him or her working with a child. Use Appendix D to analyse your colleague's positioning work and other activities. Allow your colleague to do the same for you. Think about what you learned from this collaborative learning activity.

There are many different types of assistive devices and apparatus to support children with PID:

- Walking devices (e.g. walking frames, wheeled frames, crutches and specialised walkers)
- Wheelchairs and buggies
- Standing frames
- Side-lyers
- Foot or leg splints
- Adapted utensils
- Glasses (to improve vision).

We will now look at some these in more detail to learn more about how they can assist children with PID most effectively.

Wheelchairs and buggies

Wheelchairs enable children to move or be moved from one place to another more easily. There are many types of wheelchairs, some of which are available on loan from public healthcare facilities.

Children using wheelchairs must be seated upright and comfortably. If there is a gap between a child's bottom and the wheelchair's backrest, the child needs to be repositioned to sit correctly. To position a child correctly in a wheelchair:

- Put the wheelchair's brakes on.
- Loosen the hip strap.
- Position the child's hips at the back of the seat.
- Fasten the hip strap.
- Make sure the hip strap is not too long and adjust accordingly.
- Put in the foam side supports.
- Position the lap tray.

See Appendix D for further guidelines on how to assist children in the sitting position.

Standing frames

Standing frames should be used by children who are unable to stand alone. They help by:

- Allowing them to see others at eye level and in a different way.
- Assisting them to develop stable hips and bones.
- Stretching leg, hip and knee muscles in a functional way when playing or observing others.
- Opening the lungs for deep breathing and blood circulation.
- Aiding digestion.

To position a child correctly in a standing frame:

- Ensure the child is supported to stand upright.
- Make sure the child's hips and knees are straight.

See Appendix D for further guidelines on how to assist children in the standing position.

Side-lyers

Side-lyers are assistive devices that offer children with PID different positions from lying on their backs or stomachs. Children who cannot move much by themselves need to be placed in different positions throughout the day to maintain muscle flexibility. Using variations of recommended positions, such as lying down, teaches a child with PID the feeling of different positions and movements. Children who only use a few positions tend to get stiff muscles, and may find it increasingly difficult to move over time.

Careful planning is needed to integrate different positions and activities into a child's daily programme and routine. Children should not be in one position for more than 45 minutes. Encourage them to make little movements in the equipment such as shifting their weight, moving their arms and legs, and turning their heads in every 45-minute positioning session. These basic movements can lead to more purposeful movements depending on your goals. The checklists in Appendix D can be used as a reminder of the different positions and interventions that can be used in a 24-hour daily care programme. Other aspects can be added to these checklists as they are only guides.

Splints

Each child using splints will need to be matched to the right kind according to their functional ability. It is important to find out from an occupational therapist how the splints should be used. These general guidelines apply to the use of all splints:

- Ensure splints remain clean and that they fit properly. They will need to be replaced from time to time to accommodate the child's growth.
- Keep splints away from direct sunlight and heat, as they tend to melt and lose their original form when exposed to high temperatures.
- Look for any red areas on the child's skin when removing splints. Report these observations to an occupational therapist.

Adapted utensils

There are many adapted hand devices available such as simple built-up grips for everyday eating utensils. Some children need adapted utensils to improve hand grip, hand function and for independent eating. Universal cuffs can also be used to hold spoons when eating.

Toys can be adapted according to the learner's handling abilities. It is important to allow time and opportunity for the child to use these adapted utensils or toys on a daily basis. If you are aware of children who could benefit from using adapted devices, bring this to the attention of the occupational therapist who can help you to find the most suitable devices.

Glasses

Wearing glasses is fairly common in children with PID. Glasses help to correct vision and make images clearer, which is important for optimal learning. Here are some guidelines for working with children who wear glasses:

- Ensure the child wears his or her glasses every day for constant, good vision.
- Ensure the glasses are clean and fold them carefully to put in their case when they are not being worn.
- Check that the child attends regular follow-up appointments with an optometrist to ensure their glasses are still suitable for their needs.
- Be mindful of the glare affecting the learning environment at different times of the day. This will affect children's abilities to see well and to participate in activities.

2.6. Managing medical conditions

Carers need to learn skills to cope with specific medical conditions that some learners with PID may have (e.g. seizures). You may also need to know how to use some medical apparatus to assist children with basic functioning. It is the responsibility of the family and carers to make sure there is competency to handle seizures, administer medication, use percutaneous endoscopic gastrostomy (PEG) tubes, and perform suction. If a child with these needs is accepted and placed in centre, carers and family members must work together to achieve the best possible care.

If you are uncertain how to help children with specific medical conditions or use apparatus confidently, ask a family member who has adequate knowledge, or a medical professional, what to do. Rather ask then risk harming the child through misunderstanding or a lack of knowledge.

Pressure areas and sores

- Be sure to notice any red areas on a child's body from sitting too long or an assistive device rubbing on the skin (e.g. marks on a child's hip from a wheelchair strap).
- Prevent pressure sores by encouraging children to spend less time on pressure points. Allow the child to sit, stand and lie in different positions throughout the day.
- Report pressure sores to the medical team if they get worse.

Percutaneous endoscopic gastrostomy (PEG) tubes

PEG tubes are a safe and effective way to provide food, liquids and medications (when appropriate) directly into the stomach of children who have difficulty swallowing. Keep these guidelines in mind when caring for a child who uses a PEG tube:

- Inspect the PEG tube regularly: at every feed and change of clothes. Make sure the skin and PEG tube insertion area is clean and there are no obstructions.
- Rinse the PEG tube with water before and after each feed.
- Feed the child in an upright position.

CHAPTER 3: Teaching and caring for learners with disabilities

In this chapter, we focus on understanding the learning needs of children with disabilities, and the special considerations carers and teachers need to maximise their education. We look at how to create a physical environment suitable for learning, with practical ways to improve available classroom space. We also consider the different roles of government departments in this process.

After learning how to optimise a classroom for children with PID, we look at how to group learners according to their ability levels, and use the DBE's draft learning programme guidelines (2016a) to understand awareness, transitional and interactive groupings according to particular criteria. Then we look at how to adapt learning, play and other activities for these three groups of learners. We also look at how to meaningfully incorporate learning programmes into the daily care routines of children with PID, and consider the proposed learning programmes more closely to understand their requirements and benefits.

When you have finished reading this chapter and completed the activities, you will:

- Know how different role-players contribute towards creating a suitable learning environment for children with PID.
- Adapt a classroom space to optimise learning.
- Know how to group learners according to their cognitive functioning level (awareness, transitional, interactive).
- Adapt functional, learning and play activities for the three groups of learners according to their abilities and needs.
- Know the purpose of an individual support plan (ISP) for each learner with PID.
- Know the different roles of the centre-based care teams and LSPID support teams in caring for children and the different skills they contribute to holistic care.
- Integrate a learning programme into a daily care programme for a child with PID.
- Know more about the DBE's draft learning programme for children with SPID.

3.1. Creating an environment conducive to learning

In South Africa, most special schools and care centres were started and developed by groups of parents. Parents started these projects not just to provide for the needs of their own children, but also for other children with the same learning and care needs. There are many examples of such schools that have been included in the system supported by the DBE, and evidence of how the efforts of only one or two people can impact a larger system for the improved care for all.

The classroom is an important environment for children with disabilities. It is often a home away from home. When children feel at home, or comfortable with their environment, they are more likely to reach their developmental potential. Children and adults function better in safe and pleasant spaces. There are two aspects to consider when creating a comfortable and welcoming learning space for learners with disabilities: the physical space *and* the ethos or intention of the classroom.

Too often the physical spaces that learners with disabilities are placed in for learning are small, dark and unfriendly. There are many reasons for this, including funding, but it also reflects the attitudes towards learners with disabilities and the adults caring for them. Carers and children with disabilities need a positive physical and emotional space to facilitate quality intervention and optimal learning.

The areas within the centres that are used mostly by learners need to be well planned and allow for positive learning. This includes outdoor areas and areas for carers to take short breaks during the day. We will look at how to create suitable spaces in the next section, but first we will consider the role-players involved in developing and maintaining areas for appropriate care and learning.

3.1.1 The role of government departments

As mentioned in Chapter 1, different government departments are responsible for overseeing service delivery to meet the needs of children with PID. For example, the DoH is responsible for the oversight of children’s health and physical care, the DSD for the management of services that meet children’s social well-being requirements, and the DBE for the management of services related to education. While these aspects of care are all important and should be delivered in an interconnected way that views children with disabilities holistically, services are most often delivered separately as each department has its own agenda or perspective on children’s needs. They produce policies at a macro or policy level, and at a micro or child and family level, which are very different.

It should be the aim of all interested parties to support a holistic approach to caring for children with disabilities. The different departmental roles can work well together and complement each other when providing different components of, for example, a nutrition or feeding scheme (see table below). This type of project ensures children with PID in disadvantaged communities receive adequate nutrition. This approach should be applied to other areas of service delivery to children with disabilities.

Nutrition/feeding scheme cooperation among government departments			
	Carers	Child	Community
Department of Health	Responsible for the well-being of carers and their knowledge and skill levels related to nutrition, so they can use appropriate feeding methods and meet the nutritional needs of children.	Provision of adequate nutrition and water, and placement of children.	Volunteering for family support/information workshops with community (e.g. balanced nutrition).
Department of Basic Education	Responsible for providing training on feeding skills for learners with disabilities, and supporting the learner-support teams with information on food groups and personal hygiene through the learning programme.	Skills development and provision of content to be learned, to assist learners to become independent and help them communicate their needs.	Facilitating information sessions to share children’s and carers’ successes (e.g. vegetable garden). Facilitating teaching families’ skills for independent feeding at home and expressing needs.

Department of Social Development	Employment of carers and other staff.	Provision of CDG nutrition programmes, and support of social and cultural eating traditions.	Provision of volunteers for meal times and food gardens.
Department of Public Works	Provision of appropriate work and rest areas for carers.	Provision of accessible buildings and eating areas in centres.	Facilitating community projects for building and maintenance.
Department of Transport	Public transport to work.	Provision of transport to learning centres.	Making public transport available.

3.1.2. Classroom considerations

All areas of the centre must be accessible for all children. This means that areas need to be equipped with facilities that take into consideration the needs of learners with not just physical impairments (such as wheelchair access), but also visual and hearing impairments. The areas most regularly used by children, such as the entrance, ablution facilities, classrooms and eating areas, by law must be fully accessible. Similarly, outside play areas need to be fully accessible for all types of physical and sensory impairments. For example, a swing area should allow wheelchair access; the garden should have raised flower pots for wheelchair users; and the plants should have a fragrance for those with visual impairment. Careful thought has to go into the planning and development of the physical areas of a care centre for children with disabilities.

The outdoor space is an important part of any care centre. If designed well, this can be a learning space for the children (e.g. a vegetable garden can facilitate learning about nutrition and how plants grow). It could also be a positive space to use equipment such as standing in a standing frame under a tree, rather than indoors. Being outdoors can also be a motivator for children if they enjoy the natural stimulation of the elements/weather and different noises.

While the attitude of those caring for learners with PID often determines how responsive they are (i.e. the more positive and affirming carers are the more learners respond well), the environment in which learners stay for the day is also important in determining their overall responses and progress.

Some practical considerations in designing a classroom for learners with disabilities are:

- Space allowance for wheelchair access and storage (doorway openings, turning circles in bathrooms, etc.).
- Layout of the classroom to facilitate the natural flow of activities.
- Colour choice:
 - The use of contrasting colours to separate spaces such as steps and different working areas.
 - Yellow is the brightest colour for low vision.
 - Contrasting colours for different objects (e.g. table mat/bowl/cup).
- Avoid sharp edges and table corners for safety reasons.
- Ensure optimal light (natural and artificial). This is important for learners with low vision.
- Ensure spaces are well ventilated and enable the flow of fresh air.



Figure 5: The classroom is an important environment for children with disabilities.



Activity 3A

Complete the activities and write down your answers to the questions.

1. Explain to a visitor to your classroom (or imagine that you have a visitor) how your classroom facilitates learning for children with PID and their care needs.
2. Look at the classroom you work in from a visitor's perspective. Ask yourself or your visitor:
 - a. How does your classroom meet the needs of children with disabilities?
 - b. What improvements can be made to the classroom to better meet the needs of both the carer and the children? (Think about the size of the classroom, the flow of activities, the use of the space inside and outside, access to the toilets, etc.).
 - c. How does the classroom reflect the interests and personality of the carer or teacher?
 - d. How does the classroom support play activities?

3.1.3. Grouping learners for activities

Grouping children with disabilities according to similar functional abilities, rather than age and diagnoses, helps the carer or programme implementer to work in a similar way with children at the

same level. The planning and implementation of a daily programme and activities is made easier in a group of children with similar abilities. Grouping adolescents with young children is not advisable as their developmental needs are different. Placing children into skill and ability groups also aligns with the DBE's policy statements and recommended learning programmes, which advises that learners are grouped according to levels of cognitive functioning (DBE, 2016a).

Determining learner groups

Three broad learner groups are described in the Draft Learning Programme for Children with Severe to Profound Intellectual Disability (2016a). Children are placed in one of these groups according to their ability to interact or participate in daily activities.

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

Each learner's responses and basic functioning need to be assessed or rated to determine which group they are placed in. The focus is always on what the learners can do, rather than on what they cannot. The table below shows the criteria for grouping learners with PID and will help you to assess your learners' basic functioning and physical responses, self-care and communication skills, and responses to play activities.

Criteria for grouping learners with PID

Basic functioning and physical responses			
<i>Activity</i>	<i>Awareness group</i>	<i>Transitional group</i>	<i>Interactive group</i>
Understanding and making needs known	Understands a little and makes needs known in own way.	Needs support to understand others. Makes needs known to familiar people.	Understands a fair amount. Makes needs known, even to unfamiliar people.
Moving around	Moves arms and legs. May move on floor a little.	Uses different ways of moving.	Able to move and walk, even if using assistive devices.
Hand function	Hands can feel and hold objects if placed in them.	Uses hands with assistance or in adapted situations.	Uses hands. Can use objects such as spoons.

Self-care and communication skills			
<i>Activity</i>	<i>Awareness group</i>	<i>Transitional group</i>	<i>Interactive group</i>
General tasks	Responds and follows very simple instructions.	Understands and can do a simple task with assistance.	Follows simple or multiple instructions.
Self-care skills	Needs full support in self-care activities.	Attempts to help in self-care activities.	Is independent or requires some supervision in self-care activities.
Domestic tasks	Has limited participation in domestic tasks.	Needs assistance to complete domestic tasks and adapted activities.	Needs supervision for domestic tasks.
Responses to play activities			
<i>Activity</i>	<i>Awareness group</i>	<i>Transitional group</i>	<i>Interactive group</i>
Ball play	Looks at and feels the ball. Looks at slow-moving ball. Shows preference for a ball. Attempts to touch a ball.	Holds a ball for playing. May let go of the ball. Moves a ball with hands and feet. Rolls a ball.	Throws a ball. May kick a ball. Asks for a ball. Can perform simple games with balls (e.g. Pass the Ball).

Choosing and adapting activities for ability groups

Once you have grouped learners as accurately as possible, you then need to choose and adapt activities to meet the needs of each group's functioning levels. All activities chosen for children must be at their level of skill and ability. A well-chosen activity involves the child to his or her maximum potential and is set at or slightly higher than his or her functional level. This means that carers must be able to understand how to play and adapt toys and objects to meet the learning needs of the different groups. Children who are able to achieve a skill through play and learning are motivated to do more.

In meeting the groups' needs it is important to consider the required ratio of carers to learners, the degree of support required by the learners, and the types of activities learners can perform. The table below will help you to choose and adapt activities for the three groups.

Support needed			
<i>Activity</i>	<i>Awareness group</i>	<i>Transitional group</i>	<i>Interactive group</i>
Carer : Learner ratio	1 Carer : 1 Learner	1 Carer : 2–3 Learners	1 Carer : 4+ Learners
Degree of support to be given	Full physical support to explore body, objects and the environment.	Initial physical support followed by retracting support. Full-time verbal support and supervision.	Minimal physical support. Mostly demonstration and verbal support are needed. Supervision required rather than support.
Types of activities	Sensory and motor based.	Self-care and routines. Activities using concrete and familiar objects of daily life.	Activities that promote optimal independence in self-care, basic work skills, play and leisure.
Possible adaptations to activities			
<i>Activity</i>	<i>Awareness group</i>	<i>Transitional group</i>	<i>Interactive group</i>
Understanding and making needs known	Provide full physical support.	Provide moderate physical support. Reduce support when necessary. Use adapted equipment.	Provide minimal physical support. Use best positioning. Use adapted or alternative apparatus. Give verbal support. Vary set-up or structure of activity.
Moving around	Use and talk about objects, not pictures. Provide hand-over-hand support.	Use non-verbal communication through looking/pointing/touching real-life objects. Expose learners to choice-making opportunities between two objects. Give physical and verbal guidance.	Communicate through looking/pointing/touching pictures with photographs (AAC). Give physical and verbal guidance.
Hand function	Provide hand-over-hand support. Use easy-to-grasp objects. Use objects with multisensory	Use optimal positioning. Provide hand-over-hand support and retract. Use adapted devices. Start with easy-to-manipulate objects (e.g.	Use optimal positioning. Use adapted devices. Change set-up or structure of activity. Start with easy-to-manipulate objects

	stimulation (e.g. a ball with bells inside).	big peg posting in big container), working to more difficult objects (e.g. small peg posting in small opening).	(e.g. big peg posting in big container), working to more difficult objects (e.g. small peg posting in small opening).
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Activity 3B

Read Maria's story and complete the activities.

Maria's story

Maria is a five-year-old girl with a severe global developmental delay. She lives with her mother and grandparents who are very supportive. Maria can move around on the floor using all her limbs. She tries to get up by herself, but can only manage to stand by holding onto furniture for a few seconds. Maria complains or makes moaning sounds when she is hungry, but has learned to wait her turn to get food. When she is excited, she does an activity quickly without waiting to know what to do. Maria's hands tremor, but she can hold her spoon if she is reminded. Maria loves to play with objects that have a lot of sensory input such as finger paints and play dough.

1. Plan an activity using finger paints or play dough for Maria. Think about how you will adapt the activity to enable Maria's maximum participation: What position for play will you choose? How will you communicate with Maria and convey what she is expected to do with the finger paint or play dough?
2. Choose a toy or object that Maria might enjoy and describe how you would adapt it for each of the three ability groups.

3.2 Developing individual support plans

An individual support plan (ISP) is a document that states what interventions and support a child needs to reach his or her agreed goals through participation in a learning programme.

Developing ISPs for learners with PID is a team effort. Each contributor (the child, carer, family members, therapists, doctors, social worker, etc.) brings different and unique perspectives to the planning process, and the combined insights, suggestions and ideas help to create a comprehensive ISP. Often the combined insights result in a realistic plan that effectively identifies how a child's learning programme can be adapted to meet his or her needs. Supporting learners with PID is an ongoing process of setting goals and strategies and then reviewing to see if the goal(s) were reached. The learner and family members are central to this process.

Areas of intervention	Target to be achieved	Strategy of intervention	Responsible person	Time-frame	Review date (to assess target achievement)	Comment on achievement of targets
Self-care	Toileting independence	<ul style="list-style-type: none"> Fixed toileting routines at centre and home: <i>discussion with carer and guardian</i> Toileting social story: <i>group activity</i> Integrated fine-motor perceptual activities: <i>individual/group activities</i> 	<ul style="list-style-type: none"> CSPID OT and teacher Guardian Centre personnel 	1-3 months	August 20...	

Figure 6: Sample ISP. Adapted from DBE (2016a).

An ISP should indicate the areas of support and the degree of support for or details needed about the learner.

Area of support	Degree of support / details required
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 ten metres).
Activities of daily living (ADL)	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 medications, referrals to doctors, liaison with parents, etc.
Assistive devices	Details about the checks, maintenance, review and referral of assistive devices to the DoH and other providers.
Classroom	Details about the use of classroom elements (e.g. ability grouping, available equipment and resources, and layout of classroom areas).
Centre	Details about equipment such as ramps, nappy changing area and carer-child ratio.
Family and carer	Requirements for counselling, support groups and workshops.

3.2.1 Record keeping

Record keeping may seem unnecessary and take up a lot of time after a busy day with learners. However, this is a time for carers to reflect on the day and on the learner's progress. Sometimes it feels like the progress of a child with PID is very slow, but if good records are kept it makes it easier to see how much progress the learner has actually made. Recording observations helps the care team to review the goals set in the ISP alongside the learner's development. A recorded story of progress is mostly a story of encouragement to motivate the child and the care team. Often the

beginning of the developmental journey is forgotten and it is encouraging for the team to be reminded of the goals already achieved.

It is also a good idea for a carer to keep a journal of their own learning and need for further training. You can then refer to it when there are opportunities to develop or suggest topics for further training.



Activity 3C

1. Think about different ways to record a child's progress.
2. Try to look for ways to record the small changes in a child (e.g. by taking photographs or recording videos of the responses or smiles of a child, or of a child completing activities).
3. Start implementing your ideas with some learners.

3.2.2 Support and referral pathways

Children with PID require many people to support their learning and care needs. Carers also need support, for which support structures have been developed. The LSPID support teams have the responsibility of providing support to learners, carers and care centres. However, as with all relationships, this system can either work well or be disjointed depending on the relationships and attitudes of the different team members. Understanding the job descriptions and individual roles and interests of each team member can help to build good working relationships.

Understanding team and individual roles

As mentioned in previous sections, each member of a child's care team brings different insights, professional expertise and experience. By working together, team members link knowledge and abilities across disciplines to best support carers and children with PID.

There are two main types of teams involved the care of children with PID: The centre-based team consisting of carers, implementers, facilitators, volunteers, cleaning and ground staff, etc., and the LSPID support team, which is not centre-based but brings specialised knowledge and skills to complement the care and interventions of the centre-based team.

Understanding each team's roles and the roles of individuals within these teams helps to maintain good working relationships. A good relationship between the centre-based team and the LSPID support team can be likened to the relationship between the carer and the parent of a child with PID. Sound and clear communication, understanding and respecting others' roles, and, when necessary, compromising and adjusting approaches, are all needed to effectively assist children with PID.

Responsibilities of the centre-based team

The centre-based team has the role of seeing and supporting children with disabilities on a daily basis. They have an immediate and long-term perspective of the children in that they see progress made on a daily basis over a period of time. The LSPID support team has expertise and training in specific disciplines such as physiotherapy and speech therapy, which it brings to the centre-based team to plan and implement ISPs together.

The carer's daily observations and experiences of a child in the classroom provide valuable insight for ISPs. By discussing these observations with LSPID support team members, a holistic view of a child can be reached and the most effective ISP can be drawn up. The carer is often the go-between between the parent and the LSPID support team members, and is an important link if there needs to be a combined meeting with the LSPID support team and other parties.

Responsibilities of the LSPID support team

The LSPID support team works collaboratively, sharing its skills and expertise. This means that each member of the team is familiar with all aspects of the initial assessment of a learner to plan the basic intervention. The responsibilities of the LSPID support team are:

- Capacity building of care centre staff through direct training (modelling and instructions) and workshops.
- Parental training, counselling and support.
- Regular meetings with other role-players in the centre.
- Screening and assessing learners.
- Developing ISPs.
- Grouping and compiling group support plans for learners with similar needs.
- Implementing the learning programme through the development of activities and assisting in making learning support materials.
- Facilitating the implementation of the activities with guidance on the optimal use of equipment, devices and learning support material, including toolkits.
- Monitoring the implementation of stimulation support programmes, including guidance and support for care workers.
- Appropriate referrals to public special schools where necessary.

The LSPID support team may consist of a learning support teacher, therapists (occupational, physiotherapy and speech therapy), and an educational psychologist. Understanding the different responsibilities, foci and interests of the various LSPID support team members can support effective working relationships and specific support for children with PID.

- The **learning support teacher** gives training and support for the child's learning environment, the daily learning programme and the integrated programme, as well as applying therapeutic interventions within the classroom.
- The **physiotherapist** focuses on the child's physical abilities in terms of positioning, functional movement and grading, and recommending specific exercises and assistive devices.
- The **occupational therapist** focuses on play and the grading of visual, perceptual and cognitive activities. This could involve adapting the environment to allow a child with disability to learn functional skills and to learn through play and movement.
- The **speech therapist** focuses on communication, which may involve using adaptive methods.
- The **educational psychologist** focuses on the emotional well-being of the learner (i.e. the learner's emotional, behavioural and cognitive functioning), and assists with placement in a centre that is a 'good fit' for the child. The psychologist has the additional role of contributing to the emotional and psychological well-being of the centre's staff. Counsellors may assist in giving support with the often overwhelming emotional needs of the child and family members.

- The **social worker** focuses on the social well-being of a child. This includes counselling the family, applying for grants and other needs for the general well-being of a child (e.g. food parcels). The social worker also assists in investigating suspected abuse or neglect of a child.



Activity 3D

Read Andie's story and complete the activities.

Andie's story

I know that the LSPID support teams want to help us, but sometimes they just confuse me. Like last week, they came and told me what activity I could do with a child. They showed me how to do it, but I could not get it right when they left. I am worried that when they come again they will ask me to show them, but I haven't managed to do the activity. Sometimes I try to do the activity and at other times I just know that the activity won't work for that particular child, because I am with the child every day and I know what the child can and can't do. Also the child needs time to learn a new activity.

1. Advise Andie on what she could say to the LSPID support team that would enrich the child's ISP and contribute to a good working relationship.
2. How do you think the LSPID support team and the carers at Andie's centre could work better together?
3. Describe an experience or story of your own about how the LSPID support teams and carers have worked well together at your centre. Explain what contributed to this effective working relationship.

One aspect of maintaining good working relationships with multiple team members is to remember that there is always a process to follow when seeking assistance or support from other professionals. Usually the process looks similar to this:

1. Identify the problem or need (e.g. my foot is sore).
2. Explore the reasons for the problem or need (e.g. my shoes are too small, there is a sore on my foot).
3. Know the specific request for support (e.g. I would like a bigger salary to buy new shoes or I would like someone to examine my foot to see what is wrong with it).
4. Ask for support from the most appropriate person (e.g. ask your manager for a bigger salary or ask a doctor to examine your foot).

You can see from this example that being clear about what you would like and who can help you with your specific need are important in getting the results you want. Remember this when seeking solutions for the children in your care.

3.3. Integrating a learning programme into a daily programme

Due to their medical history and experiences, children with PID function minimally. This usually means that they need a great deal of support to learn and function optimally within a daily programme. The abilities of each learner with PID differ, therefore a learning programme must be suited to individual learning and other needs of the learner.

3.3.1 Aims of a learning programme

A learning programme is based on developing skills for progress in education, movement, self-care, social interaction and communication. Every day is a learning day for a child with disability, and every activity, experience and relationship at school, at home and in the community is a learning opportunity. The general aims of a learning programme for children with PID are:

- To guide the planning and development of individual and group learning to enable them to meet their potential.
- To develop skills to meet their learning needs in various areas of their lives.
- To promote a lifelong process of learning skills and applying them to their daily lives.
- To integrate formal learning into daily routines at care centres in a constructive and effective manner.

3.3.2. Structure and principles of a learning programme

A learning programme promotes knowledge and lifelong learning, and includes different subject areas and bodies of knowledge that can be applied by children to different aspects of their development and daily lives. The learning programmes for children with PID that are promoted for use in South African care centres are aligned and adapted to the following policies and curricula:

- National Curriculum Statement Grades R–12 (NCS) (2007) updated by the Curriculum and Assessment Policy Statements (CAPS) (2012)
- National Early Learning Development Standards (NELDS) (2009)
- National Integrated Early Childhood Development Policy (2015)
- National Curriculum Framework for Learners from Birth to Four Years (NCF) (2015)
- Policy on Screening, Identification, Assessment and Support (SIAS) (2014)
- Draft Learning Programme for Children with Severe to Profound Intellectual Disability (2016)

Principles of a learning programme

A learning programme for children with PID should be underpinned by the following principles:

- All children, regardless of their disabilities, can and do learn.
- All children have their own level of ability and pace of learning, and should start learning programmes at the level appropriate to their level of skills and ability.
- All children learn through play.
- All children learn through and from experiences of play, activity and relationships.
- Every interaction is a learning opportunity for a child.
- Children need to be seen holistically and taught using an integrated approach.
- All children learn by repetition – repeating the same skill in different ways. Using the same skill in a different setting can be considered a different skill.
- Learning is life long and develops over time.

- Children with disabilities learn in all of their different contexts: at home, at a care/learning centre and in their communities.
- A successful learning programme is sensitive to a child's needs and his or her social and cultural background. It identifies a child's strengths, interests and needs, and what support he or she may need to participate and learn, and what motivates the child to persevere in learning.

3.3.3. Learning programme subjects

The DBE has responded to calls to improve learning programmes for learners with SPID and has drawn up learning programme guidelines aligned with the NCS and CAPS for Grades R–12. There are three subject areas: Communication and Language, Life Skills, and Mathematics. These subjects should be taught together as part of an integrated, holistic learning programme.

Communication and Language

The Communication and Language subject area aims to develop learners' ability to:

- Understand what is being communicated.
- Express themselves using verbal and non-verbal language, and various bodily and emotional expressions.
- Use communication to influence their environments, including building and enjoyment of relationships with others.

The three content areas for this subject are: listening and receptive skills, expressive skills, and pre-literacy skills.

Life Skills

The Life Skills subject area is aimed at guiding and preparing learners for life and successful living in society. The subject covers topics that develop learners' knowledge, skills and values in physical, social, personal, emotional and cognitive developmental areas.

This subject consists of three content areas:

- Personal and social well-being: This focuses on developing learners' knowledge of personal health and safety, and understanding their relationship with other people and the environment. It teaches learners about their rights and responsibilities.
- Physical education awareness: This focuses on the development of learners' gross and fine motor skills, and perceptual development. It includes perceptual and locomotor development, rhythm, balance and laterality. Physical growth, development, recreation and play are emphasised.
- Creative arts: This concentrates on the development of creative and aesthetic skills and knowledge through engaging in dance, music, drama and visual art activities – and adapted activities thereof. Learners should be guided to use their natural inclinations to use their imagination, manipulate and work with materials, move and make music, and tell stories. Learners should explore and develop their creative ideas based on their personal experiences, using their senses, emotions and observations.

Mathematics

The Mathematics subject area aims to develop learners' ability to:

- Develop awareness of how mathematical relationships are used in social, environmental, cultural and economic relations and situations, and are part of everyday life.
- Recognise Mathematics as a creative part of human activity.

The content areas for Mathematics are:

- Numbers, operations and relationships
- Patterns, functions and Algebra
- Space and shape (Geometry)
- Measurement, and
- Data handling.

These content areas may appear difficult to interpret for learners with PID. However, the activities mostly focus on developing pre-numeracy and emerging numeracy skills such as spatial orientation, two- and three-dimensional discrimination, understanding position and direction, sequencing activities, and telling the time.

Integrating the three subjects into a daily programme

Integrating the three subjects into a combined daily programme may be one of the biggest challenges for carers of learners with PID. You will need to familiarise yourself with the contents and expectations of a learning programme, and look at ways to integrate these into your daily routines. The following list of themes are recommended to guide and facilitate teaching and learning. They can be used as weekly themes for selecting learning and play activities.

- Me and my body
- Me and my school
- Me and my family
- Me and my home
- Senses and emotions
- Seasons
- Rights and responsibilities
- Transport
- People who help us
- Food and healthy habits
- Safety
- Sport

The table below is an example of how to integrate the three subjects of the recommended learning programme into your daily routine.

Daily programme	Communication and Language	Mathematics	Life Skills
Arrival Unpack bag	Talks about home/ride Listens and responds	Perceptual and memory skills	Routines – self-care
Morning ring Greeting, weather, news, birthdays, days of the week, songs, visual sequence – daily routine, Bible/moral story	Stories Songs Listens and responds Participates (actions/words) Talks about object, picture	Perceptual skills such as matching, counting, colours, rhymes Sequencing activities such as time (weather, news, birthdays, days of the week, visual daily routine chart) Memory activities	Movement Songs and music Routines Emotional skills Social skills
Activities of daily living Breakfast, toileting, washing hands, brushing teeth	Stories Songs Listen and responds Participates in routine and discussion (actions/words) Talks about object, picture	Perceptual skills such as matching, counting, colours, rhymes Sequencing of actions/routines	Self-care routines Gross and fine motor skills Emotional skills Social skills Basic work skills
Gross motor Physical education Balls, swings, obstacle course	Listens and responds to game instructions Participates (actions, words)	Perceptual skills such as body awareness, laterality, spatial, matching, counting, colours	Emotional skills Social skills Gross and fine motor skills Sensory skills
Discussion time (seated on the carpet)	Stories Songs Listens and responds Participates (actions, words) Talks about object, pictures, topic	Perceptual skills such as figure ground, spatial skills, matching, counting, colours, rhymes	Emotional skills Social skills Gross and fine motor skills Sensory skills

Table activity 1 (fine motor/art/play dough/puzzles)	Listens and responds Participates (actions, words) Talks about object, pictures, activity	Perceptual skills such as matching, counting, colours, rhymes, sequencing	Emotional skills Social skills Gross and fine motor skills Sensory skills
Snack time	Use activities covered in ADL	Use activities covered in ADL	Use activities covered in ADL
Structured indoor/outdoor play (construction/sand play/water play/pretend play/games)	Listens and responds Participates (actions, words) Talks about activity	Perceptual skills such as figure ground, body awareness, matching, counting, colours, rhymes	Emotional skills Social skills Gross and fine motor skills Sensory skills
Music and movement Social ring/dancing/singing/musical instruments	Stories Songs Listens and responds Participates (actions, words) Talks about object, pictures, topic	Perceptual skills such as figure ground, body awareness, matching, counting, colours, rhymes, sequencing of actions/dance	Emotional skills Social skills Gross and fine motor skills Sensory skills



Activity 3E

1. Review the example above of how to integrate the learning programme into daily routine and reflect upon your own daily routine with the children in your care.
2. Choose a theme and design an outline for a week's programme that includes all three subject areas: Communication and Language, Life Skills, and Mathematics. Use the daily programme structure to plan the programme with activities and aims.
3. Think about an activity that you use often in your class. Make a list of skills that are developed through this activity, which fall into three subjects' content areas. In other words, what communication and language skills, life skills and numeracy skills can be developed in, for example, a greet and meet activity?

3.4 Parental involvement with learning and the classroom

Some parents may want to support and learn from a carer or teacher in the classroom. There are certainly roles for parents to play in the classroom. For example, they can be an extra pair of hands and can contribute knowledge from their experience with their child. But they also need to respect that the classroom is a learning space for children and their role is to support the learning.



Activity 3F

Read Celeste's story and complete the activities.

Celeste's story

I recently went to a course about the circles of care and learning in severely disabled children. At the course, I learned that I need to work better with parents. I was excited about this, but also not sure how to include parents in helping children to learn. There is often tension in the classroom when parents are present, and the responsibilities of the carer, teacher and parent become unclear. However, parents can be of great support to a carer in the classroom. At the same time they can observe their own child and other children from a different perspective to their home context. Opposite to this, some parents don't respond to meeting requests and do not make the time to meet with me. This is also problematic as the learning progress of their child is affected negatively.

1. Think about different ways to meet with parents and attract them to meetings.
2. Think about ways that parents and carers can work together more effectively.
3. Prepare a short introduction for a meeting with parents on 'Why we need to work better together'.

CHAPTER 4: Communicating with families affected by disability

In this chapter we concentrate on how the family unit can be affected by disability, and how carers can assist families in understanding and coping with the demands of children with PID. We will look at clear communication, what it means to adopt a family-centred approach to caring for children with PID, and how to collaborate with parents in setting and reaching shared goals for their children.

When you have finished reading this chapter and completed the activities, you will be able to:

- Reflect on your communication skills and how to improve them to build effective relationships with colleagues and family members of children with PID.
- Know what is meant by a family-centred approach to supporting children with PID.
- Know guidelines on how to improve your communication skills with parents.
- Be aware of physical, behavioural and social signs children and their family members might display, which may indicate underlying problems that need to be addressed.
- Be aware of symptoms of abuse and know how to go about reporting suspected abuse.

4.1. What is effective communication?

In Chapter 2 we discussed that communication is a two-way process that involves reciprocal listening, understanding and talking. Communication skills are learned early in life and develop over time into more complex forms. However, communication skills need constant practice and development. This is evident in personal and professional relationships and teams that have become dysfunctional and ineffective due to poor communication.



Activity 4A

Think about how you communicate with your family members and how they have communicated with you in the past.

1. What are your memories and experiences of how your family communicated with you as a child and how you currently communicate with them?
2. What positive aspects of communication (e.g. listening well, empathising, encouraging others) have you learned or practised within your family context that can be applied to your professional life?
3. What skills do you feel you need to communicate more effectively with others and why?

4.1.1 Communicating with parents and other family members

Communicating with parents who have a child with disability is a two-way process that involves listening *and* talking. Good communication requires honesty and builds a good relationship on which

other support interventions and activities can be planned and developed. The well-being of children with disabilities is dependent on good communication between parents and their carers and other centre-based team members. Good communication is mutually beneficial for carers and family members in sharing responsibility for the care and support of children with PID.

Sometimes, we have to be mindful of certain considerations and dynamics in communication. For example, when communicating with LSPID support professionals, parents and other family members may feel intimidated or vulnerable because of the professional's specific skills, expertise and knowledge. At times it is difficult for both parties to be honest without being misunderstood, and the differences in perceived knowledge levels may inhibit openness and transparency. It is important for all parties to remember that their insights, life experiences and, importantly, perspectives of the child with PID, are different and exceptionally valuable in contributing to the overall understanding of the child and the development of an effective ISP. Always remember that each person, no matter their experience and background, has a particular story and reasons for their decisions and actions. Learning how to listen rather than judge while listening is a valuable skill that fosters healthy working relationships with family members.



Activity 4B

Think about what you would most like to communicate to parents of children with PID at your centre. Also think about how you, and other carers, currently communicate with parents. Complete the activities and share your ideas with colleagues at your centre.

1. Make a list of what you would like to communicate to all new parents of children with disabilities who come to your centre.
2. Choose the three most important points on your list and discuss these with your colleagues. Add any items that your colleagues share to your list.
3. At your next meeting with parents, divide the parents into groups of five. Ask each group to discuss communicating their and their children's needs with carers. Ask a representative of each group to give feedback on the points that arose in the group, and then have a whole group discussion about how the ideas could be implemented at the centre.
4. After the meeting, take steps to implement the realistic ideas that parents suggested for improving communication at the centre.

Family-centred teamwork

Family and *belonging* to a family may mean different things to different people. Family differences reflect variations in economic, cultural and social aspects of society. Family structures vary widely and we need to recognise that extended family, sibling and community members also have important roles to play. Working with different families can be challenging, and we need to be mindful that our own family experience will influence how we view other families. Making judgements about how other families operate is common, but it is not necessarily helpful in collaborative work. Families of children with PID who experience positive team work with service providers are more likely to report better

quality of life levels, experience less family stress, and see greater improvement in the performance and overall progress of their children.

In the past, many families have felt disempowered and disengaged by the medical model discussed in Chapter 1. This care model has traditionally followed a top-down approach or 'the medical professional knows best' approach, which sees parents and family members contributing very little to the planning and development of care and support for their children. It has seen parents mainly consulting with medical experts who offer suggestions for implementing solutions. While the skills and knowledge of medical professionals are crucial and valuable to the care and progress of a child with PID, they have a limited perception of the child based on their often time-limited consultations. Parents may find themselves trying to explain to medical professionals that their child can do something at home, but it is not evident to the medical professionals at the centre, treatment room or hospital. There has been a recent shift towards working more collaboratively with families and the perceptions of all interested parties are important and should be included in overall assessments.

Respecting families includes respecting their culture, language, traditions and expectations for their children, which may have been passed down from previous generations. The extended family also has a role to play within the smaller family unit and their involvement may influence the child with PID. When working with families, remember:

- The child with PID belongs to the family and is therefore the main responsibility of the family. Each child in the family unit has a different role.
- Each family has its own routine, rules, traditions and ways of doing things that keep the family together. The child with PID forms part of these routines and culture.
- Families are units (functional or dysfunctional) made up of people with different personalities, and of different ages and generations. This makes the family system dynamic and ever-changing.
- A family with a child with PID has the most experience of what it means to live with the child all day over many years. This experience is invaluable in understanding the child.

Acceptance of children with PID starts in the family. The way in which a family accepts and cares for a child with PID is an example to others in the wider family and community. Accepting and caring for a child with disability in a positive way promotes advocacy for proper care. Families are continually accepting and adjusting to their children's needs throughout their lives. For example, accepting that a baby is developmentally behind is very different to accepting that a child may require surgery or never be able to get married.

Some families see a child with disability as a burden of care, which may become the child's identity and has ramifications for the child and family members. The attitudes of centre-based and LSPID support teams can also affect the child and family. Frequently team members project an attitude of blame or judgement on families through misguided assumptions when questioning family members about a child's medical history and other care-related issues. These negative attitudes can have a direct impact on accessibility to health, education and social services for the child as certain criteria may be interpreted as not being met. This, plus the complicated referral systems for accessing support services, mean that parents often give up the fight for support and, ultimately, it is the child with PID who suffers.



Activity 4C

Read Thandi's story and reflect on your responses and similar experiences before answering the questions.

Thandi's story

I am a single mother of three children. My youngest son is profoundly disabled. I am not supported by the father who blames me for this disabled child. I don't know what I did to deserve a child with so many challenges? I am responsible for everything for my children. I am glad that I have a job which helps to feed us. I am often so tired when I am finished work that I don't have much energy to do anything. On weekends, I must clean my house and do the washing.

1. How would you begin to support Thandi to care for her child with PID?
2. Which families at your centre do you enjoy working with the most? Why? Do you have a pattern of, for example, working more with families who are involved in their child's care and pulling away from those who do not?
3. Think about a family in your centre that is not very involved with the care and activities of their child. What aspects of this family do you judge?
4. What can you learn from this family? How can you change your attitude towards them?
5. What practical ways can you think of that could help less-involved families become more involved in the care and support of their children at your centre?

4.2. Guidelines for improving communication

Parents or guardians are the leaders in families and it makes sense to develop a good working relationship with them as the main links to children with disabilities. Some guidelines on how best to include parents in the care and support of their children are:

- See parents or family members as allies you can share expertise and resources with. An ally is someone you can work with to win a war or overcome seemingly impossible circumstances. By adopting this view, family members will be assured that you are on their side.
- Persevere in striving for the best outcomes for children together. This will have the greatest impact and outcomes for the entire family and support teams.
- Look for ways to support the family as a whole. Families may change for the positive by recognising their own need for change, making decisions and being supported to implement necessary processes.
- Be kind to yourself and to the family as you work together on problem-solving and trying new ideas and interventions to support the child. Being willing to work together as a team is the first step in achieving positive outcomes for everyone involved.
- Set goals for the child through a collaborative process that includes family members and members of the centre-based and LSPID support teams. Include family members in meetings and constantly update parents on their child's progress and activities. In other words, try to

encourage the active involvement of parents in the support activities and interventions planned for their child. The better the collaboration the better the chances are of reaching shared goals.

- Offer regular opportunities at your centre for parents to come together and share their views with centre staff. Don't give up if attendance is low, but try to work out the reasons for this and adapt accordingly.

How to support families

We all need support, both personally and professionally. Caring for children with PID can be demanding and tiring, especially if they need 24-hour care. Family members who are supported cope better with the stresses and effects of disability on their lives. Supported families are also more likely to support other families. Ideas for supporting families with children with PID at your centre include small support groups for parents and/or family members, and workshops for families dealing with specific topics related to the care of their children.



Activity 4D

Read about Hannelie's experience of trying to support parents at her centre. Answer the questions and choose one support activity to implement with parents and colleagues at your centre.

Hannelie's story

Hannelie is a carer at a day-care centre. She wanted to facilitate an open-door approach to communication with parents so that they could come and see her at any time. She sent out the message: 'Please come to me if you need help.' No families came to see her and she wondered why. It turned out that some families felt her message was judgmental of their ability to cope with their children and that they somehow needed help. This was not Hannelie's intention, but how the message was interpreted.

1. Can you relate to Hannelie's experience?
2. What suggestions do you have for Hannelie to encourage parents to speak to her without making them feel judged?
3. Brainstorm ways that you could bring families together at your centre – perhaps for an event that would support families and allow them to have a lot of fun together. The idea must include parents sharing in the planning and actual doing of the event. What would be realistic to do with the help of families at your centre?
4. Choose a topic that best meets the knowledge or skills needs of parents at your centre. Plan a workshop to facilitate a discussion with parents on this topic and working together as a team.
5. Start a small support group of carers and parents at your centre to facilitate ways to help one another. Your first session could simply be a social occasion during which you get to know each other and share how you came to be at the centre.

4.1.2 Communicating concerns and observing problems

While communicating with parents regularly is important to the care and progress of children with PID; it is also important that you remain alert to any potential 'red flags' in a child's health or family's well-being that might indicate underlying problems or challenges that need to be addressed. If a family is not coping with the challenges of managing and supporting a child with PID, the centre-based or LSPID team can offer and provide the necessary support and intervention.

Signs that can alert you to issues which may need to be addressed are:

- Physical signs on a child with PID.
- Behavioural or emotional signs displayed by the child.
- Social and behavioural signs displayed by family members.

These physical signs need follow-up and extra care:

- Red areas (pressure points) on the skin
- Red areas or puss around a PEG tube
- Open wounds and sores
- Marks, cuts and bruises
- Diarrhoea
- Vomiting
- Coughing during or after feeding or drinking
- Any indication of physical abuse.

Social and behavioural signs displayed by family members that require follow-up include:

- Absent, non-communicative and uninvolved parents (e.g. non-attendance at meetings organised to discuss matters relating to their child).
- Family members look exhausted and stressed.
- Centre fees are outstanding.

Children with PID may need to be protected from their own family members or people in their home environment if they are being neglected or abused. The WHO describes child abuse as a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress. Child abuse can happen anywhere and child abusers come from all walks of life. It could be anyone who has access to a child and is in a position to mistreat him or her.

There are different types of child abuse: physical abuse, sexual abuse, emotional or psychological abuse, neglect and exploitation. It is important to be aware of signs of child abuse such as unexplained burns, cuts, bruises, or welts in the shape of an objects, bite marks, fear of adults, apathy, and depression.

Unfortunately, sexual abuse is not uncommon among children and youth with PID, and may be recognised by the following signs: inappropriate interest or knowledge of sexual acts, nightmares and bed wetting, drastic changes in appetite, fear of a particular person, and self-mutilating behaviour (self-inflicted cuts, sores and/or burns).

The Children's Amendment Act (No. 41 of 2007) requires any person with the responsibility of caring for children (e.g. teachers, social workers, doctors), who suspects that a child has been abused, to report this to the provincial DSD. In child sexual abuse cases, special investigations must be carried out including taking specimens as forensic evidence. The child may have been exposed to sexually transmitted infections and HIV, and treatment is given when test results are positive. Parents or caregivers should be counselled about the potential risk of the child having been infected with HIV. The caregiver will be asked for his or her consent for an HIV test to be done on the child.

Should you suspect any form of abuse to be taking place, you should by no means take it upon yourself to confront suspected parties or investigate the matter. Report it to the appropriate authorities such as Childline, Lifeline or the South African Police Service.



Activity 4E

Read Meisie's story and write down your answers to the questions.

Meisie's story

Three-year-old Meisie is the youngest daughter of a single mother. Meisie, her mother and other siblings live with the mother's parents. Meisie's mother is the only adult who is employed. Meisie has been coming to the care centre for a few years. Lately she has been crying when she arrives at the centre. Meisie can't talk so it is difficult to know why she is crying so much. Meisie is fed through a PEG tube and is looking a bit thin.

1. What concerning signs is Meisie showing that may indicate underlying problems which need to be addressed with her mother?
2. What potentially can be done to deal with the possible problems?
3. What is your role in communicating these signs and possible problems to other members of the centre-based and LSPID teams?

CHAPTER 5: Caring for the carer

In this chapter, we take a closer look at the role of carers in supporting children with disabilities. We focus on the skills and abilities carers need to foster and maintain sound working relationships with the children in their care, their families, and colleagues in care centres. We highlight the exceptional worth of carers and the work they do, and encourage carers to acknowledge this and care not only for their children/learners, but also for themselves. We offer practical tips on how to cope with the daily pressures of working as a carer, the physical and emotional demands of the job, and how to manage the stress and avoid burnout. We further explore the importance of working collaboratively with carers and other professionals at care centres, and what this means practically.

When you have finished reading this chapter and completed the activities, you will be able to:

- Reflect on your identity as a carer and the value you place on your job.
- Recognise the knowledge and skills you have to be a carer, and the skills you may still need to develop.
- Identify areas in your life that need to change for you to care for yourself and function optimally.
- Recognise areas of stress and tension in your life, and know the signs of burnout.
- Understand what collaboration is more clearly and how it assists in creating a less stressful workplace for carers.
- Understand how to appreciate individuals' roles and contributions to teams in the workplace.

5.1 Knowing oneself as a carer

In our context, the term 'carer' can refer to any person who takes care of and supports the development of a child with disability. This could be a parent, an employed carer, a neighbour, a therapist, etc. The focus throughout this manual has been on the carer at a day-care centre, but the recommended activities and exercises could also be by a parent or any other person caring for a learner with disability in another context (e.g. at home).

One of the challenges of working with children with disabilities is that, because the children are often stigmatised, discriminated against and isolated, so too are their carers. This may mean that the work of a carer is not recognised or is referred to in a way that shows no appreciation for their vital role. Some carers are discouraged by these negative attitudes and the child with disability's care may be compromised. Unfortunately, negative attitudes towards the care of persons with disabilities exist across the wider social system, beyond the family unit, which lead to entrenched beliefs and attitudes in society. However, every small action of advocacy and lobbying to recognise the important work carers do can assist in changing the broader systems for the better.

The skills and roles of a carer

To perform their role successfully, carers need to learn and practise physical and emotional skills, which include:

- An understanding of disability and related conditions.
- Skills for physically handling a child with disability such as seating a child in a wheelchair or positioning him or her in various positions for different activities.

- The ability to work effectively in a team.
- Excellent communication skills.

To be a valuable team member and excellent carer, carers need to realise that they are exceptionally valuable and that their contribution to the lives of children with disabilities is of exceptional worth. If *you* can recognise your contribution to the life of a child with disability, others will also notice and come to respect both you and the child. Empowerment is knowing one's value and wanting to share this with others. What is also noteworthy is that the amount of effort a carer puts into the care and support of a child with PID will be reciprocated through the child's progress and learning.

The role of carers may vary and extend beyond meeting the physical, emotional and social needs of children to include the responsibility of facilitating or guiding their learning. There is often a tension between the roles of caring and teaching. Children with disabilities need both to live well in society. Therefore it is important that carers view their role as including caring and teaching.

In smaller centres, carers may have a more varied role that also involves cleaning and preparing meals for children. There is no wrong or right description of a carer's role, but it is best practice for the roles to be child-centred. Child-centred practices achieve better outcomes and progress for children with PID *and* for those caring for and teaching them.

To become more child-centred, centres need their staff and communities to adjust their attitudes and behaviours towards children with PID. This may mean adopting a new respect and appreciation for the valuable roles of children with PID, their unique abilities, and their motivation to overcome physical limitations. A child-centred approach concentrates on what they are able to do with the right support, care, protection and education, rather than on what they are unable to do. Carers have a role to play in modelling this approach towards children with disabilities in the communities in which they work. When community members see the respectful way carers relate to the children in their care, the same attitude is often mimicked and adopted.



Activity 5A

Reflect on your identity and role as a carer before completing the activities.

1. Draw a picture that represents you as a carer. Use symbols to represent what you do and how you see yourself in your role. Ask someone to review your drawing (or try to view your drawing from another person's perspective) and write down what your picture communicates.
2. Write a paragraph about yourself to give to a group of new parents or colleagues that explains who you are, what you do, and the reasons why you work with children with disabilities.
3. How has working with children with disabilities changed you and your perceptions of people, life and the world around you? What changes do you think we would see if broader society had experiences similar to yours?
4. How does the way in which you treat children in your care reflect a child-centred approach and affirm their dignity?
5. How you would like to develop or grow as a carer?

5.2 Self-care in the workplace

Caring for yourself enables you to care for others. Many people think that self-care is something you do at home, not at work, but it is essential that self-care becomes normalised in the workplace, especially for among those caring for others. Self-care refers to the way in which carers treat themselves, which should reflect the same kindness, understanding and thoughtfulness they show to the children in their care.

Carers often choose their jobs because of their passion for helping vulnerable children, which requires exceptional empathy, kindness and self-sacrificial love. This often means, however, that the last people they think about helping is themselves. Self-care is not something to feel guilty about and is not being selfish or self-centred. Self-care is a way of keeping inner resources (emotions, understanding, etc.) alive and well to maintain the capacity or energy to care for others. People who take self-care seriously tend to have greater motivation and experience greater personal growth despite difficulties and challenges. They are often well connected with other people and make a positive contribution to their lives. Giving to others and receiving from others could be seen as a circle of care.

Self-care affects all aspects of our lives – physical, mental and spiritual – and involves:

- Getting adequate nutrition.
- Exercising regularly.
- Getting enough sleep.
- Making time to relax and socialise.
- Having and practising a hobby or interest.

5.2.1 Skills and ideas for self-care

Self-care is not about comparing or judging yourself against other people. It's about valuing your own worth and contribution to your family's, friends' and colleagues' lives. Genuinely practising self-care includes:

- Recognising that making mistakes is a human experience, and being kind and understanding rather than judgemental about your own mistakes and failures.
- Apologising for mistakes and learning from the experience.
- Not allowing negative emotions to take over your thinking, but rather focusing on the positive aspects of your behaviour and the achievements of those around you. Make a conscious effort to be grateful for these positive aspects of your life and work.
- Knowing the limitations of your skills and abilities. This means that you are not embarrassed to ask for help when it is needed. You can also help others who ask for your help in areas in which you are more skilled and confident. The mutual support of colleagues is beneficial for everyone.
- Being less critical of children, their families and your colleagues until you have sought to understand their views. Each person has his or her own story, abilities, skills and limitations. To accept this in ourselves helps us to accept others.

Practising self-care as part of the workplace routine is likely to benefit any centre and should not be viewed as a waste of time. Good self-care in centres can result in less sick-leave being taken and organisational goals being attained more effectively.

Here are some more practical ideas for incorporating self-care into your daily work routines:

- Notice how you are feeling each day. When you ask children how they are, ask yourself too.
- Take time each day to be quiet by yourself, even if for only a few minutes.
- Reflect on yourself and your achievements during the day. Be honest and focus on the positive. Also try to identify potential causes of stress, anxiety and feeling stuck, and think about practical ways to address or remedy them.
- When remembering past stories that perhaps hurt you, think about how you could be more caring towards yourself.
- Be conscious of the things you are grateful for during the day.
- Listen to yourself. Trust your gut feelings and emotions.
- Look for meaning and enjoyment in daily chores at work and at home.
- Join a group (e.g. a choir, community or hobby group) or start one that can be of support to you. Make contact with others and consciously build relationships with people who uplift you.
- Make opportunities for laughter and fun. Laughter relieves tension.
- Celebrate, enjoy and share the achievements of everyone in the workplace.
- Be aware of your needs and ask for help.
- Be willing to receive kindness and help from others.
- Take your annual leave and use it for proper relaxation activities.

Developing resilience

Resilience is the ability to keep going forward and cope with life, despite challenges and problems. Resilient people can overcome huge challenges, which might crush others under the same circumstances, and become stronger through the process. Part of being resilient is learning to accept support from others. You can consciously develop resilience by:

- Determining realistic goals and aspirations for your life and working towards them.
- Maintaining a sense of humour and an optimistic perspective when facing challenges.
- Talking about your challenges with supportive friends, family and colleagues.
- Being positive about yourself as you make progress towards your goals.
- Knowing when to ask for help and actually asking for it.



Activity 5B

Find a quiet place to sit in a relaxing environment. Read and think about the questions before writing down your answers.

1. How we use our time is a reflection of some of our life choices, so it is helpful to be aware of your own 24-hour and weekly activities. Draw a pie chart showing the amount of time you spend in a day doing different things (sleeping, working, doing chores, exercising/playing sport, etc.). Then work out what this looks like for your average week.
 - What activity takes up most of your time?
 - What activities re-energise you?

- What changes can you make to include more activities that make you feel cared for?
 - What stops you from caring for yourself? What can you realistically do about this?
2. Think about a challenging experience you had with a person at your workplace.
 - Write down how you treated yourself during the encounter.
 - How could practising some of the principles of self-care have helped you to manage the incident better?
 3. Think about a time in your life when you showed resilience.
 - What support did you receive from others during this time?
 - What other things did you practise to maintain resilience?

5.2.2. Caring for your body while working with children

Self-care includes being mindful of how you move your body when caring for children with disabilities. When you are moving, lifting and positioning children, be aware of how you use your body, particularly your back, so that you do not injure yourself.

Use these steps as a guide for lifting and moving a child with disability:

- First think about the situation and decide what needs to be done (plan). This includes determining how heavy and how big or tall the child is.
- Make sure the two surfaces are as close as possible and remove all obstacles (prepare).
- Ask for help when needed (assist).
- Stand close to the surface and/or learner (position).
- Place your legs one in front of the other, with your feet facing the direction you are going to move (ready).
- Keep your back straight and your stomach muscles tight (steady).
- Use your legs, not your back, to lift.

When moving a child from one surface to another:

- Carry the child as close as possible to your body.
- Avoid twisting your body.



Activity 5C

Do this activity with a colleague at your centre.

1. Plan and demonstrate the steps you will follow to move a child lying on the floor in a side-lyer to a changing station.
2. While you are demonstrating the steps, explain to your colleague why you are using your body the way that you are.



Figure 7: Be mindful of how you move your body when caring for children with disabilities.

5.2.3 Managing stress

Stress and tension are typical human experiences to be expected in any relationships, including work ones. People show or manage their stress in different ways (e.g. keeping quiet, having emotional outbursts, withdrawing, abusing substances). How a person responds to stress is a choice, most often based on that person's intentions and personality. Unresolved stress and tension may affect a person's well-being and the attitude of a team.

Children also get stressed and upset, and while some children with disabilities may not be able to say how they feel in words, they can communicate their emotions through body language and behaviour. Sometimes children with PID need help to identify their feelings by you interpreting them for them – for example, 'I see tears in your eyes, you must be sad' or 'You are smiling, you must be happy'.

A balanced lifestyle can help you to manage stress better, and could involve:

- Ensuring you have enough work to be busy, but not overloaded.
- Taking adequate time to rest and relax away from work.
- Getting enough sleep.
- Getting adequate nutrition through healthy eating.
- Making social contact with other people who are positive and encouraging.
- Practising other self-care ideas.

Not managing stress well and not caring for yourself can lead to burnout. This is caused by prolonged emotional and physical stress and exhaustion, and is a serious threat to all carers. If you feel exhausted all the time and every day is a bad day, you may be on the road to burnout. Signs of burnout are:

- Having less energy than usual.
- Feeling constantly exhausted, even after sleeping or taking leave.
- Getting sick easily and often.
- Neglecting your own needs because you are too busy or don't really care anymore.



Activity 5D

Find a quiet place to sit in a relaxing environment. Read the questions and think carefully about your answers.

1. What makes you anxious or stressed?
2. How do you manage stress and tension in your life?
3. What causes stress in your team at work?
4. What are the positives of teamwork at your centre?
5. How do these positives keep the team together?
6. How can the causes of stress be addressed using the strengths of the team?

5.3 Collaborative relationships in the workplace

Collaboration involves a team of two or more people, a process (working together) and a purpose (shared goals). All three elements are important for successful collaboration. If two or more people are working together without shared goals, they are simply co-operating. Working collaboratively means that all of the team members give and receive for a common purpose. It is more than just teamwork. It involves sharing or pooling knowledge, resources and skills to achieve a common goal such as the development of a child's skills. Collaboration at a centre means that families and carers work as a team, each with their own role, to achieve common goals for the well-being of children with PID. Working together involves sharing ideas and communicating regularly.

There are many benefits to working collaboratively:

- Individuals are able to develop skills and strengths.
- Knowledge is shared and solutions are found collectively, leading to effective long-term solutions.
- Better relationships are forged among colleagues.
- Role clarification is often achieved, enabling individuals to take ownership of a particular part of the team's efforts.
- A consistency in managing children's behaviour, learning and overall progress is achieved.
- More is achieved together than by individuals working on their own.

Some ideas for fostering collaborative practice are:

- Including the family and relevant centre-based and LSPID support team members in a child's assessment process.
- Developing an ISP for a child with his or her family and support teams, which enables team members to see and know their responsibilities in the various contexts in which the child lives and learns.
- Encouraging parents to reinforce the shared goals set for their children.
- Involving volunteers or peers/siblings in a child's learning and daily programme. This would develop a community support system for learners with disabilities.
- Calling on specialists or people with particular skills to addresses specific challenges (e.g. asking a speech therapist or parent to suggest alternative communication methods to be able to communicate with their child).

5.3.1. Barriers to collaborative practice

Although you might think it is easier to work independently of parents and other family members, it will be less satisfying and have fewer beneficial outcomes. If carers and parents don't communicate and share ideas, and a mistake is made or something goes wrong, it makes it easy for one party to blame the other. This obviously can lead to the development of tense situations and a stressful work environment. The quality of our personal relationships has a great effect on our well-being. Good relationships contribute to positive emotions with less stress and tension. Some of the commonly expressed barriers to collaboration with family members and centre colleagues are:

- Judgemental attitudes towards families and their care of their children.
- Poor communication from families.
- Non-payment of centre fees.
- Late arrival or non-attendance at parent meetings.
- Power imbalances in some relationships.
- Misplaced or unrealistic expectations.
- The manner in which people communicate (e.g. angry outbursts, using patronising language)
- Blame and accusation of work not well done.
- Misunderstanding of individuals' roles and the contexts in which people work and live.
- Misunderstanding or limited knowledge of issues related to working with children with disabilities.
- A lack of transparency.

These barriers can be overcome through better communication, less judgment, being willing to listen to people's reasons for their behaviour, and eventually setting shared goals together.



Activity 5E

Read Esther's story and Salene's story, and think about how you can relate to their experiences. Answer the questions and then discuss your responses with your colleagues.

Esther's story

Every day, each child is sent to the centre with a bag that includes a change of clothes, nappies if necessary, and a snack box. Jan arrived this morning at the centre with no nappies in his bag. I was so cross with the mother and could not believe that she could do this to me. What was she thinking and where was I going to get spare nappies for the day? I confronted the mother about this when she fetched Jan. I was embarrassed by my quick judgement of her when I heard her explanation about what had happened in her home that day. I have learned that I should first listen to parents' stories before I judge their behaviour.

Salene's story

I am a carer working at a day-care centre. I started this centre because I have my own child with a disability. Members of the surrounding community told me that there was a disabled child living in another house. I went to the house and the parents told me that their child was not disabled, but I could see that she was. I encouraged them to just try my centre and they didn't have to do anything. After some time, the child joined my centre. She has been here for a while now. The parents always thank me for telling them about this centre because they see progress in their child.

1. Think about an experience you have had that is similar to Esther's. What did you learn from your experience?
2. Do you think Salene, the parents at her centre and the community have a similar vision and purpose for her centre? Why do you say this?
3. How would you describe the core values of Salene's centre?
4. Do the parents support this purpose and vision?
5. As a group, make a poster that depicts the purpose and vision of your centre.

Role clarity within teams

In Chapter 3, we looked at some of the roles of team members within the centre-based and LSPID support teams. The way in which individuals within these teams view themselves and their responsibilities affects their behaviour and actions in performing their role at work. It is therefore important that people have clarity on their roles and responsibilities in the workplace. A job description defines the roles and tasks that need to be done within an employment agreement.

A job description should be clear so that the roles expected of people are not open to multiple interpretations. For example, 'disability advocacy' may be interpreted by one person as a formal role to be fulfilled during work hours through formal structures and events, while another person may view this role as promoting the rights of people with disabilities among family and friends.

Understanding different people's roles, defined responsibilities, and skills and abilities, aids collaboration because individuals know exactly what their duties are and can proceed without worrying about stepping on people's toes or neglecting their responsibilities. A person's responsibilities and duties should be matched with his or her skill and knowledge levels. When there is a mismatch of team members' duties and skills level, they perform below the expectations of the

team, become insecure and potentially defensive about their work, or disengage and neglect their responsibilities. Harmony and a true sense of collaboration among team members can be achieved when people are fulfilling roles of which they are fully capable and allow them to apply their skills and knowledge fully.

Team members' personalities also play a role in working collaboratively. For example, a shy person who prefers working with individuals or small groups, will be uncomfortable speaking to a large audience at an open day, but would play an important role in meeting with individual families. When we appreciate each other's unique characteristics, we can appreciate working in a team more because we realise that other people's strengths can compensate for our weaknesses and vice versa.



Activity 5F

Read Jesta's story and think about how you can relate to her experiences. Write down your answers to the questions and then complete the activity with the help of your colleagues.

Jesta's story

Jesta works at a hospital as a therapy assistant. She completed her schooling up to Grade 4. Jesta is a gentle person who has lots of compassion for mothers of children with disabilities. When a young mother of a child with disability came to the hospital, she was mostly sent to see Jesta. Although counselling was not strictly in Jesta's job description, she was often chosen as the preferred counsellor. Counselling became part of her role and she was good at it.

1. What role does Jesta have in her team for which she is not formally qualified?
2. How would you ensure that her work was recognised and valued by the team?
3. What strengths do you have that are valuable in your workplace?
4. What role(s) in your team would you like to develop in line with your strengths?
5. Plan and hold a discussion group with your colleagues. On small pieces of paper, write down something you appreciate about each of your colleagues or the strengths they display in the workplace. Exchange these notes with one another.

CHAPTER 6: Using community and support networks

In this chapter, we look at the relationships children with disabilities have with people and organisations beyond their families and carers. We focus on the other circles in the circles of care model discussed in Chapter 1. We consider the importance of community members having relationships with children with disabilities and the benefits these bring to all parties involved. We discuss practical ideas on how to foster meaningful and truly mutually beneficial relationships with community members.

When you have finished reading this chapter and completed the activities, you will be able to:

- Reflect on the attitudes of the immediate community towards children at your centre in terms of their inclusivity of children with disabilities.
- Know the benefits to communities of including children with disabilities in community initiatives.
- Have practical ideas on how to build mutually beneficial relationships with members of your centre's community.
- Identify events, places and programmes that you could facilitate or use to foster relationships with service providers and other organisations in your centre's community.
- Consider how to implement or improve a volunteer programme at your centre so that it supports the staff and engages community members meaningfully.

6.1 Belonging to a community

One of our basic needs is to belong to a group. We each have a need to be connected with others because we are social beings who desire relationship. Being part of a group helps us to find our identity within a group. We also build our self-esteem by successfully doing activities with groups. People who feel they belong to a group make valuable contributions to their immediate communities and to wider society. People who are different, such as children with disabilities, also desire and need opportunities to belong to a group or community of people.

If a group isolates or excludes a person, this has the effect of disempowering or lowering that person's self-esteem. Being excluded from a group communicates to a person that he or she is not valued. Exclusion may be something as small as turning ones back to a person, or whispering within a select group, or it may be obvious such as not being invited to events or being mocked verbally. Society can also exclude people with disabilities unintentionally by not taking their needs into consideration, such as having no wheelchair ramps to a clinic, making the building inaccessible to people with certain disabilities.

Negative attitudes towards people with disabilities remain one of the biggest barriers to community participation. We often judge and avoid people with disabilities as we don't understand their ways of communicating and life experiences, or may be fearful of interacting with them. This is destructive to fostering mutually beneficial relationships. Every person has a valuable contribution to make to community life, and children with disabilities should be able to integrate into a community and feel accepted by others. The South African ideal of *ubuntu* remains unrealised when individuals, groups and communities are dominated by judgement, fear and divisive attitudes.

The family is a child's first experience of being accepted (or not) by a group, and it is important that families are well supported so that they can accept, love and care for a child with disability. The

positive attitudes of family members and carers are examples to community members of how to accept and care for children with disabilities.



Activity 6A

Read Tasneem's story and think about how you can relate to her experiences. Write down your answers to the questions and then complete the activity with the help of your colleagues.

Tasneem's story

My friend has wanted a child for a long time, but she has had a few miscarriages. The last one happened when she was 11 weeks pregnant. She came to visit me after her last miscarriage. My daughter, who has Down syndrome, moved towards her and just wanted to sit on her lap. They enjoyed each other's company and had fun together. My friend sent me a message afterwards to say that her soul had been healed through my daughter sitting with her during the visit. I am so pleased to have a child who can help people in this way.

1. Have you ever experienced the 'healing power' of children with disabilities?
2. In what ways are children with disabilities in your centre or neighbourhood included or excluded? What are the possible reasons for this?
3. Plan a workshop with parents to discuss the inclusion of children at your centre into the community. Keep the focus of the discussion on the needs of the children and their families to integrate with the community. Make lists of possible opportunities, venues and events in the community. At the end of the workshop, reflect on what support is still needed.

6.1.1 Benefits to the community of involving children with disabilities

The benefits of integrating children with disabilities into the community are experienced by everyone who gets involved:

- The community learns to care and empathise with the vulnerable in their environment. They learn that everyone has the potential to become vulnerable (e.g. in old age or through circumstance).
- The community becomes aware of the needs of people with disabilities and starts to lobby for positive changes in their environment such as better access to facilities through the provision of assistive aids (e.g. wheelchair ramps or lifts in buildings).
- The community learns to work together around a specific need (e.g. lobbying for the improvement of transport to schools). Learning to work together fosters healthy relationships among community members.
- The inclusion of children with disabilities means that they have potential as adults to contribute to the community through disability employment initiatives.
- Including children with disabilities empowers them with opportunities to develop to their potential and change their and others' lives for the better.

6.2 Building relationships with the community

There are many practical ways for community members to get involved with the care and education of children with disabilities at a centre or at home. Some ideas include:

- Involving community members in outings.
- Relationships with service providers.
- Partnerships with education/training institutions.
- Accessible community spaces.
- Open days.
- Volunteer programmes.

6.2.1 Involving community members in outings

Outings are always fun although they involve a lot of preparation. Outings offer the opportunity for children with disabilities to be in the community and for community members to engage with them. The venues chosen for outings ideally should be places of mutual interest to the children and the community members (e.g. the beach, parks, shops, museums, sport grounds, concerts).

Outings help to develop relationships with the community members who manage and maintain the venues. Through these visits, people in the community learn about children with disabilities and this understanding can lead to empathy and positive relationships over time. The children also learn from interacting with the environment through new experiences.

Outings are also a good way to include parents in their child's learning programme, and for parents to assist carers and meet other parents at the same time.



Activity 6B

Read Cheryl's story and think about what you can do to enrich the experiences of the children in your care.

Cheryl's story

Jayden is a boy in my class. He screamed every time he went out of the centre. When there were outings, Jayden was always left behind as he made such a noise. I thought that perhaps he needed some experience of what it was like to walk safely with me and the other children in the community. We went every day for a short walk in the community. After a while, Jayden started to shout less and looked at the cars and people walking in the streets. He got used to the short walks and even enjoyed being outside. We can now include him in outings. On Friday, we are going to visit a farm and Jayden is going with us. What we do every day helps children to feel included.

1. Do any children in your care have the same reactions as Jayden during outings?
2. What can you apply from the story to potentially help these children?

6.2.2. Relationships with service providers

We often rely on people we know, or with whom we have relationships, for assistance and services. For example, if your car breaks down you are more likely to contact a friend or family member who is a mechanic than someone you hardly know. Professionally, we rely on contacts within our network for assistance. It is important to develop good relationships with service providers in your centre's community so that you can work together to solve problems when they arise. Good professional relationships ensure that people know who to contact for what, and who can be relied on to deliver quality services when needed. It is also important to connect with people in essential services such as the police, nurses and other organisations. You never know when you may need to rely on the services of government departments and other organisations in, for example, an emergency scenario.



Activity 6C

Lize's story, unfortunately, is quite common. Read it and discuss the questions to the questions with your colleagues so that you share information about service providers in your community. You can refer back to Chapter 4 for how to report suspected abuse.

Lize's story

I got a phone call on a Friday afternoon telling me that one of the children at my care centre was at a house and being abused. I went to the house and was quite shocked to see what was happening. I decided to report it to the police and I took the child with me. I had to fill in lots of paperwork. I hoped the child was going to be protected. I didn't know what to do because a police officer removed the child from me for questioning. I was in a state of shock and panic as I knew that the child trusted me and would not talk to the police. The social worker was not available until Monday. I did not know what to do or even how I felt. I was confused and wondered if I did the right thing. In the end the child was placed in a place of safety.

1. What good decisions did Lize make?
2. What decisions or actions of Lize would you change? Why?
3. How can your centre develop better relationships with the police and social workers servicing your community?
4. How can the police, clinics and other services keep children with disabilities safe and protected from abuse and violence?

6.2.3 Partnerships with education/training institutions

If a care centre for children with disabilities develops relationships with universities or other education/training institutions, this can be mutually beneficial: these institutions need placements for their students to complete the practical components of their courses, while care centres always need extra hands to assist with the children. Education/training institutions may bring new ideas and approaches that carers can learn and try out in their centres, while students learn practical know-

how from carers about what works in particular contexts for children with disabilities. These reciprocal relationships of exchanging ideas and sharing professional practices only help to improve the overall care provided for children with disabilities.

Developing relationships with other care centres and schools may also be a positive and mutually beneficial process. Being able to share resources and opportunities with each other will help you to expose the children in your care to more community initiatives and learning experiences.

6.2.4 Accessible community spaces

Sport stadiums, municipality buildings, concert halls and other recreational spaces are intended to be accessible to and shared by all community members. These places can be used to engage community members and children with disabilities. In reality, however, people with disabilities are often excluded from these community spaces as they are not accessible by wheelchair or do not cater for the use of other devices. The atmosphere in some of these spaces can be hostile to including people with disabilities, but this should not allow them to stop community spaces from being used for relationship-building activities.

6.2.5 Open days

Open days are an opportunity for community members to visit care centres. Often there is no reason for community members to visit a special care centre unless there is an open day or an invitation is extended to them. Open days are important as they communicate that the care centre is open to community involvement.

Open days can also encourage parents and their children to engage with the community, which may want to be supportive. Families often find it difficult to communicate their need for acceptance in a community, but open days help them to do this in a natural and open way. Many centres plan sport days, music concerts, plays and displays of arts/crafts that the community can attend. Community members and parents can then volunteer to assist with the organisation and running of these events.

6.2.6 Volunteers

A centre that is open to volunteers can create positive and mutually beneficial relationships with the community. There are many people who have time available and want to make a difference through volunteering. Centres may need volunteers to help feed children and for specific playtimes to improve individual attention and intervention. Their shared, positive accounts of their volunteering experiences help to improve the wider community's understanding of and attitudes towards children with disabilities. Other ways that centres can benefit from having volunteers include:

- Volunteers can become a valuable support for staff (e.g. relieving them for short breaks).
- Volunteers become part of the centre's professional network, helping the centre to access resources in the community.
- Children from the community can volunteer to play with children at the centre and learn skills from one another.
- Teenagers considering careers in the health services and education could work-shadow carers at the centre.

Suggestions for volunteer programmes

While volunteers provide great support, they can also become a burden if they are not shown how to behave and what to do. Volunteers need to be orientated to understand children with disabilities,

and taught the basics of caring and supporting carers. Without guidance, volunteers can fall into the trap of feeling sorry for children with PID. Pity is unhelpful as it focuses on what the children cannot do rather than on what they can. Empathy and support for children with disabilities is required to motivate and encourage them to feel empowered. When implementing a volunteer programme:

- Ensure there is a co-ordinator at the centre who can welcome and orientate volunteers.
- Encourage consistency and commitment from volunteers for fixed period of time.
- Foster mutual respect among volunteers and staff by defining roles and reporting structures, and communicating clearly about processes and responsibilities.
- Clarify roles and times for the volunteers for specific activities such meal times.
- Try to match volunteers' interests with their roles at the centre.
- Select volunteers carefully. Choose people who do not have major needs themselves, which would place a burden on staff and children at the centre.
- Develop good relationships with volunteers so that you have long-term commitment.
- Monitor the volunteer programme regularly and ask for feedback from volunteers and staff. Use this feedback to improve processes at the centre.



Activity 6D

Reflect with colleagues on how your centre engages with the community. Then choose one or more tasks from the list that will help your centre to build mutually beneficial relationships with community members.

1. What community spaces in your area could be used for community engagement events? Plan to visit to one of these spaces.
2. Plan a workshop with parents to discuss community spaces or buildings that are inaccessible to children with disabilities. Make a list of these places and discuss ways in which they could be made accessible to wheelchair users and the elderly.
3. Prepare a 10-minute talk for a group of volunteers or other social group about the integration of children with disabilities into the community. In your talk include why communities need people with disabilities, and how to interact with them with respect and dignity. Tell a story about what you have learned through your relationship with a child with disability, and what this means to you as a member of the community.
4. Prepare a short talk for new volunteers at your centre to prepare them for their tasks and duties. What information do you think would help them feel confident about playing and working with children with disabilities?

CHAPTER 7: Understanding the wider context of disability

In Chapter 1 we explained the relationships children with disabilities have with people and organisations, from their family members to government departments, and service providers in different sectors such as education and health. Children with disabilities are therefore part of a social system affected by the implementation of policy and legislation, attitudes from the community, intervention from carers, and family life. Children with disabilities, in turn, have an influence on these circles or components of the system, and their needs and participation in communities affect policy and legislative changes at different levels.

In this chapter, we highlight some of the influential policies and legislation within the wider system of national and international government and organisations that impact children with disabilities and their carers.

When you have finished reading this chapter and completed the activities, you will:

- Know the purpose of policy.
- Know the guidelines on assessing children with disabilities provided by the World Health Organisation (WHO) in the International Classification of Functioning, Disability and Health Framework (ICF).
- Be familiar with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).
- Know the names of various pieces of South African legislation and policies that promote the rights of children with disabilities.
- Know where to find more references on international and national policies related to the equitable treatment of people with disabilities.

7.1. What is policy?

Policy documents have been developed to guide service providers on the best way to support children with disabilities and their families. Policy documents can influence how a child is taught, cared for, supported and included in society. Similarly, the needs of children with disabilities have guided the development of policies. Some policies arise from legislation that is adopted by governments, while others are adopted by organisations that play a significant role in caring and supporting children with disabilities. The many different types and versions of policies can be confusing, but certain themes are common to all of them: caring for children with disabilities with respect and dignity, the inclusion of children with disabilities in society, and that a disability does not define who a person is. Often it is more important to understand the spirit of the policy and its intended purpose, rather than the detail of its guidelines.

7.2 International policies and policy frameworks

7.2.1 International Classification of Functioning, Disability and Health

The ICF was developed by the WHO and is used widely as a guide to assessing children with disabilities. We referred to this classification document in Chapter 2. It is a policy that offers

guidelines on how to assess and plan interventions, and support children with disabilities, by evaluating:

- **Health condition.** The ICF advises starting an assessment by identifying a diagnosed health condition (e.g. Down syndrome, cerebral palsy). This is because health conditions often determine and influence a child’s abilities or skills, and expected level of development in the physical, cognitive and social/behavioural areas.
- **Body structure** refers to the physical parts of a child’s body, while **body function** refers to the physiological functions (e.g. breathing). Impairments affecting these structures and functions denote difficulties causing loss (e.g. visual impairment).
- **Activity** is the ability of a child to do a task or action (e.g. walking). Activity limitation is a difficulty an individual may have in doing an activity without support (e.g. walking with a walking frame).
- **Participation** refers to the child taking part in an activity (e.g. watching a soccer game). Participation restrictions are limitations such as not being able to see the soccer players.
- **Environmental factors** refer to the physical and social aspects in the environment or society that affect the other components. An example of a physical factor could be accessibility to school buildings.
- **Personal factors** include attitudes that a child with disability may face.

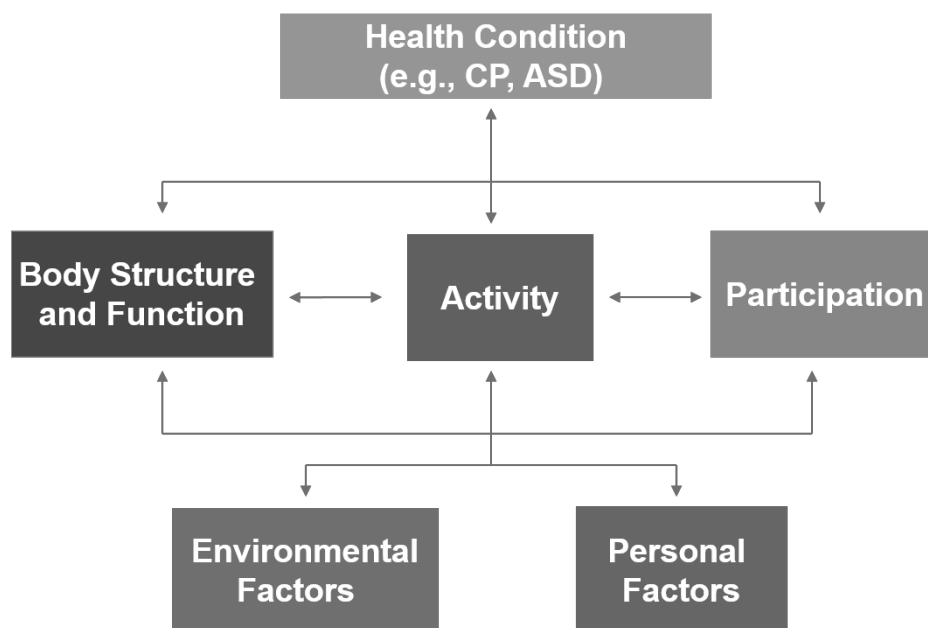


Figure 8: Components of the ICF's assessment guidelines.

With the intention of making the ICF guidelines more user-friendly, CanChild adapted the guidelines using 'F-words' that focus on six key developmental areas (Figure 9):

- Health condition = Health condition
- Body structure and function = Fitness
- Activity = Function
- Participation = Friends

- Environmental factors = Family
- Personal factors = Fun
- Future refers to the long-term planning, expectations and outlook children, their families and those supporting them may have for them and their lives.

Using these guidelines to assess children in your care ensures a holistic view of each child's assessment and ISP.

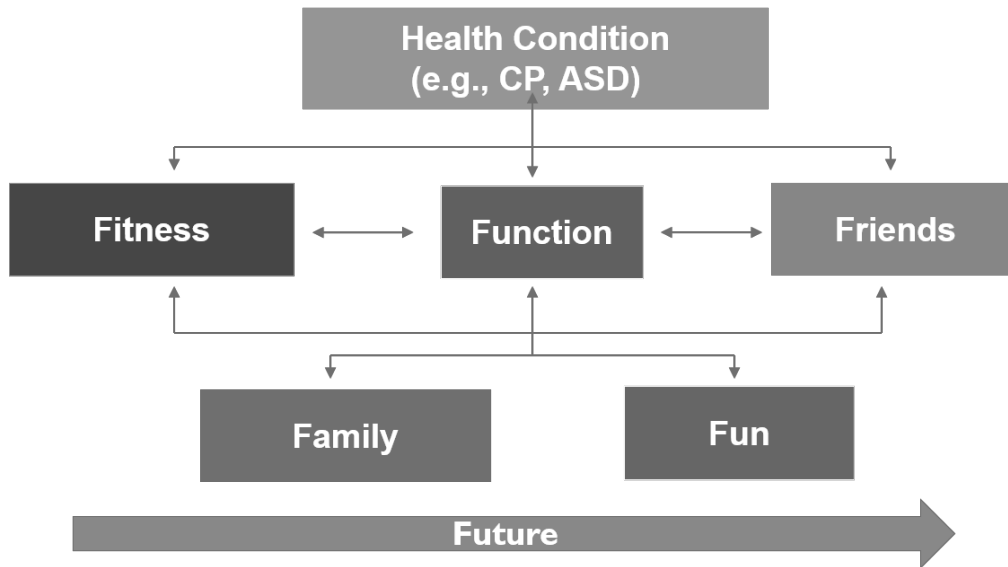


Figure 9: Adapted ICF assessment guidelines using CanChild's 'F-words'.

7.2.2 The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

South Africa signed the UNCRPD in 2007. This convention aims to promote, protect and ensure the full and equal human rights and fundamental freedoms of all people with disabilities. It encourages respect and dignity, and the key principles (specifically Articles 10, 23, 24 and 26) emphasise the rights of children with disabilities to:

- Be educated in an inclusive education system, close to their home.
- Have access to appropriate health care services including assistive devices.
- Be integrated into family and community life.
- Be protected against cruel and inhumane treatment.

The convention also emphasises that *all* children must have the opportunity to develop to their full potential and are entitled to a sense of dignity and self-worth. The convention is a good basis on which legislation and other policies can be developed.



Activity 7A

Read the UNCRPD to learn more about this important example of international policy to assist children with disabilities. The document is available at:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

7.3. National policies and policy frameworks

South Africa has some remarkable pieces of legislation and policies in place that support the rights of persons with disabilities. These policies indicate the intentions of government to care for people and children with disabilities. Although it is not important to know the specifics of the policies, unless you need them for research or legal purposes, it is good to know that South African legislation protects and makes provision for the education and care of children with disabilities.

Some policies that may be useful to you include:

- Education White Paper 6: Special Needs Education (Department of Education, 2001)
This policy emphasises the importance of involving caregivers in the education of learners with special education needs. It promotes education for all children in the education system, irrespective of their level of disability and other factors.
- The Draft Education Policy for the Provision of Quality Education and Support for Children with Severe to Profound Intellectual Disability (DBE, 2016b)
The purpose of this policy is to:
 - Direct the introduction of inclusive and quality education for children with disabilities.
 - Recognise that education is a right of children with disabilities.
 - Recognise that the needs of children with disabilities are complex and lifelong, and that every government department has a role to play in meeting these needs.
 - Promote community integration and networks of care.
 - Promote a learning programme for children with disabilities which involves early intervention from birth to four years, and educational opportunities from five to eighteen years, which support potential employment opportunities for learners when they are adults.
 - Promote learning for children with disabilities in all learning environments, from home care to formal schooling.
- White Paper on the Rights of Persons with Disabilities (WPRPD) (DSD, 2015)
The WPRPD was guided by the UNCRPD and was accepted by government in 2015. This white paper aims to inform the promotion and protection of the rights of people with disabilities in South Africa. It highlights the responsibility of different levels of government, of the family and individuals in attaining equitable treatment of people with disabilities.
- The Mental Health Care Act (No. 17 of 2002) and the Children's Amendment Act (No. 41 of 2007) also make provisions for the care of children with disabilities.



Activity 7B

Read Lebo's story. Write down your answers to the questions, and complete the poster-making activity.

Lebo's story

Lebo is a four-year-old girl who recently joined a special care centre. Lebo has been looked after by her mother since birth. She is a happy girl with a good relationship with her mother. Her mother carries her on her back to attend the care centre. Lebo is able to sit but her legs are stiff. She does not have a wheelchair. Her mother is too scared to go to the doctor so doesn't know why Lebo is unable to walk. The community helped the mother to find the special care centre as they noticed she needed help. Lebo is small and underweight, and is fed by her mother. However, she has full use of her upper limbs and has the potential to eat by herself. She has poor concentration and does not seem interested in most things. She does not speak and rarely responds to verbal communication. She enjoys it when the staff play silly games like peek-a-boo, but does not attempt to copy what they do. Lebo is fully dependent on a carer for all self-care activities and wears a nappy.

1. Which of Lebo's rights are not currently being fulfilled?
2. How could you help Lebo to attain some of her rights through your role as a carer at the centre?
3. Choose one of the policies mentioned in this chapter and create a poster of one or more of the rights promoted by this policy. Use this poster to create awareness of the rights of children with disabilities at your centre and in the community.

CHAPTER 8: Knowing more about specific disabilities

This chapter differs from the other chapters in this manual because it does not focus on the circles of care model of caring for children with disabilities. Rather it aims to equip you with information about particular health conditions and diagnoses of children with disabilities, which will help you to know how to better care for children with these conditions. We have focused on the most common conditions seen by carers. You are encouraged to do further reading on all the conditions you may encounter so that you understand children's limitations and challenges more thoroughly.

When you have finished reading this chapter and completed the activities, you will:

- Know more about some of the common health conditions affecting children with disabilities such as Down syndrome, cerebral palsy, autism spectrum disorder, foetal alcohol syndrome (FAS) and global development delay.
- Know the most appropriate interventions that can be used to care and support children suffering from certain conditions.
- Know sources for further reading about the conditions.

8.1 Introduction

Many conditions influence child development. Often there is no clear answer for a developmental delay, even though doctors have done many tests. Doctors may offer a diagnosis of severe global developmental delay if a child is severely delayed, even though no real cause can be determined. Children with intellectual disabilities have many limitations in all areas of development, which cause them to learn slowly and do activities at a simple level. Some of the most common conditions are: Down syndrome, cerebral palsy, autism spectrum disorder, and foetal alcohol syndrome (FAS).

There are many lesser known conditions such as Angelman syndrome and Rett syndrome that you may have come across. Diagnosis is made by investigating and evaluating the child's history, how he or she moves, behaves and plays, and any other health symptoms or indicators such as seizures and blood test results. Observing how a child participates and interacts with others and objects in the environment forms part of the diagnosis. The diagnosed health condition then offers possible reasons for how the child's body works (body functions and structure, and limitations thereof), the child's skills and abilities (what activities he or she can or cannot do), and the child's ability to have relationships with others (how he or she relates and participates with others).



Activity 8A

Choose a common health condition and complete these tasks:

1. Google the name of the condition and read about it on the various websites that come up in your search.
2. Ask other carers or LSPID support team members more about the condition and share what you have learned from your reading.

8.2 Down syndrome

Children born with Down syndrome have an extra chromosome 21 (trisomy 21) as a result of faulty cell division pre-birth. Children with Down syndrome may take longer to develop abilities in all developmental areas. With early intervention, support and stimulation, children with Down syndrome can develop optimally. The exact cause of Down syndrome is currently unknown. It is not related to race, the age of the mother (although there is an increased risk for children of older mothers), religion or socio-economic status and is one of the most common genetic conditions. The incidence is estimated to be one in every 650 live births.

People with Down syndrome have similar facial features: a small head, slanted eyes, small and low-set ears, a small mouth with often a large tongue, and a flat nose bridge. Their bodies may have low muscle tone and short fingers, and they often experience visual difficulties. As with any health condition, there is a range of abilities in children with Down syndrome. Some have a basic ability to read and write, while others do not. Language development usually is the most delayed area of development.

Intervention

Early intervention is important. It is critical that the family is able to be involved, to understand and to support the child's development. Children with Down syndrome can become independent in their daily functioning, with the possibility of sheltered employment as adults. Children with Down syndrome respond well to stimulation and input, and benefit from loving homes, appropriate medical care, early intervention, educational and vocational services.

8.3 Cerebral palsy

Cerebral palsy literally means 'brain paralysis'. It is 'a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occur in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, epilepsy and secondary musculoskeletal problems' (Bax, et al., 2005). In other words, this is a permanent condition, but the damage to the young brain is a once-off occurrence and the injury does not change. Children with cerebral palsy have a movement disorder with activity limitations, as well as sensory, cognitive, communication and other difficulties. Cerebral palsy has an influence on the whole development of a child.

The differences among children with cerebral palsy can be quite vast, which is the result of when and where in the child's brain the injury happened. For example, a premature baby who had a brain bleed at 30 weeks of growth could have diplegia, which means that the legs are more affected than the arms. The severity of cerebral palsy will determine if a child needs a wheelchair to move around or if he or she can walk and talk, but with limitations.

Cerebral palsy is divided into groups to help health workers assist children most effectively:

Where do you see the problem?

- Arms are more affected than the legs = paraplegic or quadriplegic (all four limbs involved)
- Legs are more affected than the arms = diplegic
- One side more affected the other = hemiplegic

What does the problem look like?

- Stiff = spastic
- Stiff and loose = dyskinetic/dystonic
- Shaking = ataxic

Although these groupings seem quite precise, practically it remains challenging to describe children as clearly as this. Children often have a combination of symptoms, so it is always better to be open-minded about diagnoses and observe children well.

Intervention

Children with cerebral palsy experience difficulties across many areas of development. They therefore need a multi-disciplinary and multi-system approach to support their development and reach their potential. Most children with cerebral palsy are motivated to move and engage with others. They may need assistive devices to help them to move, sit and stand (e.g. walking and standing frames). If they don't move enough and use different positions, their muscles tend to shorten and develop into contractures at the joints (hips, knees and elbows), which may require surgery and other procedures. The way in which they plan and co-ordinate their movements makes doing activities challenging, including ADL activities. Children with cerebral palsy can be supported, taught and guided to move and play in more efficient ways. With practice, some children's movements may improve, enabling some independence in dressing and other daily chores.

It is important that you don't judge children's cognitive abilities by looking at their physical movements. Some children with cerebral palsy, who cannot move well physically, have average intelligence. You should always remain open to a child's potential.

8.4 Autism spectrum disorder

Autism was first described about 100 years ago. It was first noticed in adults who were withdrawn, but was later seen in children. There are three basic aspects to autism:

- Impaired communication.
- Poor social interaction. Children have difficulty sharing pleasure with others and participating in activities that require practices such as turn-taking.
- Stereotypical movements and behaviours (e.g. children may be rigid or obsessive about certain objects lining up next to each other, or need to follow exactly the same routine to get dressed every day).

Intervention

Various approaches have been recommended for children with autism with some positive results. However, there is no single approach that is better than the other. Developing a relationship with a child with autism is key to making any difference in their abilities. If the main problem is social engagement and communication, developing relationships is the main focus. This is not easy as it takes a long time, requiring patience and the ability to understand the level and needs of the child. Interventions recommended for children with autism spectrum disorder include:

- Behavioural therapy.
- Social skills training.

- Psychotherapy involving parents/caregivers and the child, which may incorporate play therapy.
- Speech therapy with AAC.
- Music therapy.
- Medication is usually symptomatic (e.g. neuroleptics for aggression and anti-epileptics for seizures). Specific drug therapies for autism spectrum disorder have been disappointing.
- Education is usually carried out in special schools and highly structured programmes produce the best results.

8.5 Foetal alcohol spectrum disorders

Foetal alcohol spectrum disorders (FASD) is an umbrella term that includes all possible disorders associated with pre-natal alcohol exposure. Alcohol can affect the development of a foetus during pregnancy because it is toxic to the growing organs in the body, including the brain. The influence on the child is related to the amount of alcohol consumed (binge or ongoing drinking) and at what stage it was consumed during the pregnancy. Children with FASD may present with a variety of learning, behavioural and psychological problems, without having any physical abnormalities. The different types of FASD are:

- Foetal Alcohol Syndrome (FAS): This is the most severe form and a leading cause of intellectual disability. It is a preventable condition. Children with FAS tend to have: a small head size, slow growth (in height and weight) and possible brain damage (learning, attention and co-ordination impairments, difficulty developing relationships). There may also be specific features present, such as a long, smooth, upper lip, small openings for the eyes, and heart defects.
- Alcohol Related Neurodevelopmental Disorders (ARND): Children with ARND have mild brain damage, but show few of the other obvious signs or symptoms of FAS. Children with this condition are often incorrectly labelled as naughty, hyperactive and/or with attention deficit disorder (ADHD) symptoms.
- Alcohol Related Birth Defects (ARBD): Children with ARBD have mothers with a history of alcohol abuse during their pregnancies. These children may have malfunctioning organs, often affecting the heart, eyes, ears and bones.
- Partial FAS (PFAS): A child with PFAS usually has some of the facial and physical signs of FAS, but is not as severely affected.

FASD is a preventable condition. Prevention is complex, but includes supporting alcohol and drug abusers through programmes. Other preventive measures include:

- Raising public awareness of the dangers of alcohol use.
- Treatment centres for pregnant women.
- Early intervention with realistic expectations.
- Communication and language development programmes.
- Helping parents, especially those affected by alcohol abuse.

Intervention

Children with FAS need much developmental support. Often children who have FAS are born into families that, for social reasons, have experienced trauma. Programmes that support the development of children with FAS also have to include aspects for supporting the family. Parents

need to be involved with their child to support development. Sometimes play therapy can help in the healing of family trauma. Early intervention is critical for children born with FAS, not only for their development, but also to enable family intervention and support.

8.6 Global developmental delay

There are many conditions, including rare genetic conditions, which can cause a global or broad delay across all areas of development – physical, cognitive and social/behavioural. Some children diagnosed with global developmental delay may have other clear diagnoses, such as Rett syndrome or Angelman syndrome, but many children do not.

Intervention

The intervention will be based on the abilities and skills observed in a child. This follows a general support programme that starts with what can the child do and supports him or her to learn and develop more skills and abilities. Goals are set for these children in much the same as they would be set for a child without disabilities.



Activity 8B

Choose one of these recommended resources to read and learn more about conditions affecting children with PID:

Angelman syndrome: <https://www.angelman.org/what-is-as/>

Sotos syndrome: <https://rarediseases.org/rare-diseases/sotos-syndrome/>

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Additional resources

- American Association on Intellectual and Developmental Disabilities (AAIDD): <http://aaid.org/> [Accessed 25 August 2019].
- CanChild: <https://www.canchild.ca/> [Accessed 25 August 2019].
- Cape Mental Health: Learning for Life. <http://www.capementalhealth.co.za/learning.html> [Accessed 25 August 2019].
- Encourage Play: <https://www.encourageplay.com/> [Accessed 25 August 2019].
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Appendix A: Physical development chart

RECORD SHEET
6
(page 1)

EVALUATION OF A CHILD'S LEVEL OF PHYSICAL DEVELOPMENT

Name: _____
Birth date: _____
Date: _____

Note: Although on these guides physical and mental skills are separated, the two are often closely interrelated. These charts show roughly the average age that a normal child develops different skills. But there is great variation within what is normal.

PHYSICAL DEVELOPMENT	Average age skills begin	3 months	6 months	9 months	1 year	2 years	3 years	5 years	What to do if a child is behind
Head and trunk control	lifts head part way up	holds head up high and well	holds head up high and well	holds head up well when lifted	moves and holds head easily in all directions				Activities to improve head and trunk control (see p. 302).
Rolling		rolls belly to back	rolls back to belly	rolls over and over easily in play					Activities to develop rolling and twisting (see p. 304).
Sitting		sits with some support	sits with hand support	begins to sit without support	sits well without support	twists and moves easily while sitting			Work on sitting. Special seating if needed (p. 308).
Crawling and walking		begins to creep	scots or crawls	pulls to standing	takes steps	walks	walks easily backward	hops on one foot	Activities to improve balance (see p. 306).
Arm and hand control	grips finger put into hand	begins to reach towards objects	reaches and grasps with whole hand	passes object from one hand to other	grasps with thumb and forefinger	grasps with thumb and forefinger		throws and catches ball	Eye-hand activities. Use toys and games to develop hand and finger control (see p. 305).
Seeing	follows close object with eyes	enjoys bright colors/shapes	recognizes different faces	eyes focus on far object	looks at small things/pictures	looks at small things/pictures			Have eyes checked (see p. 452). If poor, see Chapter 30.
Hearing	moves or cries at a loud noise	responds to mother's voice	enjoys rhythmic music	understands simple words	understands "POUCH YOUR NOSE"	hears clearly and understands most simple language			Have hearing checked. If poor, see Chapter 31.

Source: David Werner (2015)

Appendix B: Mental and social development chart

EVALUATION OF A CHILD'S LEVEL OF MENTAL AND SOCIAL DEVELOPMENT

Name: _____
 Birth date: _____
 Date: _____








MENTAL DEVELOPMENT	Average age skills begin	3 months	6 months	9 months	1 year	2 years	3 years	5 years	What to do if a child is behind
Communication and language	cries when wet or hungry	coos when comfortable	makes simple sounds	uses certain sounds for different things	begins to use simple words	begins to use words together	uses simple sentences	speaks and sing often to child. If needed, develop alternatives to speech (p. 313).	
Social Behavior	smiles when hungry or uncomfortable	smiles when smiled at	smiles when smiled at	begins to understand and respond to "NO!"	likes to be praised after completing simple tasks	likes to be praised after completing simple tasks	interacts with both adults and children	Consider trying behavioral approach to social behavior (see p. 349).	
Self-care	sucks breast	takes everything to mouth	chews solid food	begins to feed self	takes off simple clothes	takes off simple clothes	bathes with simple work	Encourage child to help self if possible. Use behavioral approach to learning (see p. 350).	
Attention and interest	smiles when smiled at	smiles when smiled at	develops strong attachments to caretakers	takes longer interest in toys and activities	begins to do simple things when asked	begins to do simple things when asked	builds playthings with several pieces	Early stimulation activities (see Chapter 35). Provide toys and 'fun' objects.	
Play	grasps things placed in hand	plays with own body	begins to enjoy first social games (peek-a-boo)	imitates and copies people	begins to play with other children	begins to play with other children	plays independently with children and toys	Guided play, lots of stimulation and interaction with other children.	
Intelligence and learning	cries when hungry or uncomfortable	recognizes mother	recognizes several people	looks for toys that fall out of sight	copies simple actions	points to things when asked	follows simple instructions	Early stimulation (p. 316). Lots of toys, talk, and step-by-step training.	





RECORD SHEET 6 (page 2)



Put a **circle** around the level of development that the child is now at in each area.
 Put a **square** around the skill to the right of the one you circled, and focus training on that skill.
 If the child has reached an age and has not mastered the corresponding level of skill, special training may be needed.

Source: David Werner (2015)

Appendix C: Cognitive milestones checklist

	<p>Newborn</p> <ul style="list-style-type: none"> • Sees objects that are 8–12 inches away from his/her face. • Is sensitive to sounds close by. • Startles to loud noises by arching back, kicking legs and flailing arms.
	<p>1 month</p> <ul style="list-style-type: none"> • Watches objects and faces briefly and follows moving object with eyes. • Startles to loud noises by arching back, kicking legs and flailing arms.
	<p>2 months</p> <ul style="list-style-type: none"> • Follows moving object, such as rattle or toy, with eyes. • Recognises familiar people at a distance. • Cries or fusses if bored. • Startles to loud noises.
	<p>3 months</p> <ul style="list-style-type: none"> • Recognises breast or bottle. • Follows movement by turning head. • Startles at loud noises.
	<p>4 months</p> <ul style="list-style-type: none"> • Watches moving objects, moves eyes from side to side to watch. • Communicates if happy or sad. • Watches faces and looks at your face while feeding. • Reaches for toys and brings toys to mouth.
	<p>6 months</p> <ul style="list-style-type: none"> • Uses hands and mouth to explore the world. • Transfers objects from hand to hand. • Tries to get things that are out of reach. • Looks around at things.
	<p>9 months</p> <ul style="list-style-type: none"> • Watches an object as it falls. • Looks for objects that he/she saw you hide. • Transfers things smoothly from hand to hand. • Plays 'peek-a-boo'. • Uses thumb and index finger to pick things up, such as cereal Os. • Turns pages in a book. • Puts things in mouth.

	<p>12 months</p> <ul style="list-style-type: none"> • Puts objects in and out of containers. • Looks at the correct picture when it is named. • Bangs things together. • Begins to use common objects correctly (drinks from a cup, brushes hair). • Follows simple directions, such as 'pick up your book'. • Explores things by banging, shaking or throwing. • Pokes with index finger. • Lets go of things without help.
	<p>18 months</p> <ul style="list-style-type: none"> • Scribbles with crayon or pencil. • Points to at least one body part. • Follows one-step directions without any gestures (for example, sits when you say 'sit'). • Knows what common objects are for, such as a phone, brush or spoon. • Points to get the attention of others. • Shows interest in a stuffed animal or doll, and plays pretend. • Enjoys books, stories and songs. • Turns pages of a book.
	<p>2 years</p> <ul style="list-style-type: none"> • Builds a tower of four or more blocks. • Finds things even when hidden under two or more covers. • Explores how things work by touching them and trying them out. • Begins to sort shapes and colours. • Follows two-step directions such as, 'pick up your truck and put it on the shelf'. • Plays simple pretend or make-believe games. • Names items in a book such as a dog, cat, car or baby. • Completes sentences and rhymes in familiar books.
	<p>3 years</p> <ul style="list-style-type: none"> • Does puzzles with three or four pieces. • Draws or copies a circle with crayon or pencil. • Plays make-believe with dolls, animals and people. • Uses imagination to create stories or play. • Matches and sorts objects by shape and colour. • Works toys with buttons, levers and moving parts (for example, makes mechanical toys work). • Knows what 'two' means. • Turns pages one at a time. • Knows common colours. • Screws and unscrews jar lids, and turns door handles.

	<p>4 years</p> <ul style="list-style-type: none"> • Copies simple shapes. • Understands the concepts of 'same' and 'different'. • Follows instructions with two or three steps. • Understands the concept of counting and may know numbers. • Draws a person with two to four body parts. • Begins to understand time. • Knows basic colours. • Uses scissors. • Copies letters. • Plays board games or card games. • Tells you what he thinks will happen next in a story.
	<p>5 years</p> <ul style="list-style-type: none"> • Counts 10 or more objects. • Names at least four colours correctly. • Understands items used every day such as food or money. • Draws a person with at least six body parts. • Copies a triangle and other geometric shapes. • Understands the concept of time. • Prints some letters and numbers. • Recognises own printed name and may be able to write name.

Source: Adapted from

<http://helpmegrowmn.org/HMG/DevelopMilestone/CognitiveMilestones/index.html>

Appendix D: Positioning/Alignment checklist

Positioning/Alignment Checklist		Yes	No
Sitting	Head upright, comfortable and well-supported at the bottom of the skull; no contact with the ears		
	Arms supported, in front, shoulders level, elbows not too high		
	Sitting right back against backrest and lap strap fastened; able to slide fingers between strap and body		
	Body not twisted or markedly leaning to one side		
	Legs in neutral or slightly apart, not touching each other; thighs well supported, but back of knee not touching the seat		
	Feet supported, with shoes		
	Does the child have deformities that are accommodated in the position out of neutral?		
	Has the buggy or wheelchair been reviewed in the last 6–12 months?		
Standing	Back is straight		
	Hips facing forward		
	Feet firmly on surface, toes facing forward, in shoes		
	Arms supported, in front, shoulders level, elbows not too high		
Side-lying	Back supported against back rest or firm surface like a wall		
	Head on pillow and bottom arm slightly forward		
	Bottom leg as straight as possible		
	Top leg supported, bent at the knee		
	Alternate sides, unless specified otherwise by physiotherapist		
Supine	Head level with chin slightly tucked		
	Arms in the middle, relaxed		
	Legs open, uncrossed, supported on wedge or pillows, with feet well supported		

Appendix E: 24-hour management checklist

	Yes	No
Postural management: Is the child being positioned in <i>at least</i> three different positions during the morning, afternoon and evening?		
Has the child been prepared for a position through an explanation and gentle movements or a massage?		
Is the child well positioned in a buggy or wheelchair?		
Is the child able to lie on his/her tummy? Have you adapted and varied the tummy lying position?		
Is the child encouraged to move as much as possible, even if moving on the floor?		
Has the child been positioned in a standing frame (if the child can't stand by him/herself)? Are the hips and knees straight? Is the back upright and the arms supported on a table?		
Can the child play on a table while sitting or standing?		
Communication: Are you talking or signing to the child during activities?		
Are you making eye contact with the child? Are you using the child's name during contact times?		
Activities of daily living: Are the child's teeth brushed after meals?		
Does the child need help with dressing and undressing while sitting or standing?		
Is the child eating a balanced diet? Is the child drinking enough water?		
Play: Does the child play during positioning?		
Goal setting: Is there a shared goal in the team? Do the parents share this goal? Are the parents continuing with the programme at home?		
Carer: Are the carers caring for their backs during transfers and lifting?		

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