Republic of Namibia

EARLY IDENTIFICATION AND INTERVENTION SERVICES FOR YOUNG CHILDREN WITH DEVELOPMENTAL DELAYS AND DISABILITIES IN NAMIBIA

Understanding developmental delays and disabilities

3

UNITED NATIONS NAMIBIA

EARLY IDENTIFICATION AND INTERVENTION SERVICES FOR YOUNG CHILDREN WITH DEVELOPMENTAL DELAYS AND DISABILITIES IN NAMIBIA

MANUAL 3:

Understanding developmental delays and disabilities

Republic of Namibia

Namibia Statistics Agency

UNPRPD MPTF

Partnership on the Rights of Persons with Disabilities

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These manuals were produced by Dr Hetta van Niekerk, Educational Psychologist under the supervision of the UNICEF Namibia Country Office. Inputs were received from individuals, parents, representatives of organizations of persons with disabilities and disability service providers, non-governmental organizations and institutions of higher learning. In addition, the Ministries of Health and Social Services; Education, Arts and Culture, Gender Equality, Poverty Eradication and Social Welfare, Office of the President: Disability Affairs; as well as health experts from both the private and public sectors also contributed.

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The findings, interpretations and conclusions expressed in this document are those of the author and do not necessarily reflect the policies or views of UNICEF or the United Nations.

It is hoped that these manuals will contribute to further enhancing the capacities of individuals, parents and institutions in the early identification, assessment and referral to services of children with disabilities before formal education.

Editing, layout and design by Jo Rogge.

Sen Pang
UN Resident Coordinator in Namibia

FOREWORD

> The essence of our effort is to see that every child has a chance. We must assure each an equal opportunity not to become equal, but to become different – to realize whatever unique potential of body, mind and spirit he or she possesses.
>
> • John Martin Fischer

Namibia has committed to attaining the Sustainable Development Goals (SDGs) by the year 2030. Early childhood development is key to Goal 4 of the SDGs:

"Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all." Similarly, target 4.2 states: *"By 2030 ensure that all girls and boys have access to quality early childhood development, care and pre-primary education so that they are ready for primary education."*

During October 2019, the United Nations Children's Fund (UNICEF) Namibia facilitated an analysis of the scope and quality of currently available global good practice on the early identification and early intervention (IEIE) services for young children with disabilities and developmental delays in Namibia. It also identified the need to a develop a training manual for different service providers. This manual will focus on providing both service providers and parents with practical information on how to identify children with disabilities as early as possible and where to refer them for early assessment and early intervention.

During January-February 2020, extensive focus group discussions were held with a range of stakeholders involved in service provision to children with developmental delays and disabilities in Namibia. Barriers, gaps, as well as strengths, in terms of current service delivery, were identified. Data was also collected by means of an electronic questionnaire from educational institutions, disability organisations and health professionals. The contents of this manual are consistent with broad themes that emerged from consultations with over 200 stakeholders from all 14 regions of Namibia.

Service delivery is organised to be child-centred and family-focused, and if applicable, multidisciplinary in nature. The empowerment of parents and guardians of young children with developmental delays and disabilities, is most important.

Ester Anna Nghipondoka
Minister of Education, Arts and Culture

PREFACE

Early childhood spans the developmental period from conception to eight years of age. The child's first 1000 days - from conception to two years of age - are the most critical in child development as a child's brain develops rapidly during this stage and neural connections are formed.

When a child's brain fails to get what it expects and needs, especially during the most sensitive and rapid periods of development early in life, the amount of effort required to set it back on track later in life is enormous and optimal outcomes are far less likely.

The early years of a child's life provide an important window of opportunity to prepare a solid foundation for health, social well-being, lifelong learning and participation, and to prevent potential delays in development and disabilities. Early identification of disabilities in children is crucial to ensure future access to the appropriate intervention and support needed, to reach their full potential. Appropriate early intervention can remove or reduce the risk of secondary issues related to ongoing developmental difficulties.

Consistent with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), disability is conceptualised as an interaction between the person's impairment and a variety of barriers that may prevent the individual's full enjoyment of life situations to the same extent as others. Moreover, from a human rights perspective, all children – with or without developmental delays and disabilities – should have similar opportunities with a view to optimally developing their potential.

This manual is intended to guide all stakeholders involved with children with developmental delays and disabilities in early childhood. It focuses on the improvement of service delivery in early identification of varied development and disabilities, as well as effective intervention. The manual further provides information for parents and/or guardians about their children's developmental issues, and guidance and support in caring for them.

The Parent and Guardian Manual contains practical and useful information for training purposes. This manual can be used as resource together with additional materials for existing workshops and courses with these caregivers. Manuals 1 to 4 are intended for study and research purposes for all involved with young children with disabilities.

Responsive caregiving of young children with developmental delays or disabilities is approached from an IECD perspective in which the healthcare system, ECD programmes and parents and/or guardians collaborate with one another. Information selected from the theoretical manuals (1 – 4), is concisely presented, practically applied and graphically supported. It is important to point out that stigma and discrimination against children with disabilities and labelling them must be avoided at all costs. Working with young children with disabilities requires a carefully personalised approach. The importance of meaningful parental involvement in their children's early years and ensuring access to early childhood development services for the child with a disability are emphasised.

Alexia Manombe-Ncube
Deputy Minister for Disability Affairs

ACRONYMS & ABBREVIATIONS

AAC	Augmentative and Alternative Communication
AAP	American Academy of Pediatrics
ABI	Acquired Brain Injury
ABR	Auditory Brainstem Response
ADHD	Attention Deficit / Hyperactivity Disorder
ADL	Activities of Daily Living
AED	Anti-Epileptic Drug
APA	American Psychiatric Association
APD	Association for Persons with Disabilities
ARBD	Alcohol Related Birth Defects
ARND	Alcohol Related Neurodevelopmental Disorder
ASC	Autism Spectrum Conditions
ASD	Autism Spectrum Disorder
CA	Chronological Age
CBR	Community Based Rehabilitation
CCN	Complex Communication Needs
CNS	Central Nervous System
CP	Cerebral Palsy
DD	Developmental Disability
DS	Down Syndrome
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ECD	Early Childhood Development
ECI	Early Childhood Intervention
EEG	Electroencephologram
FAE	Foetal Alcohol Effects
FAS	Foetal Alcohol Syndrome
FASD	Foetal Alcohol Spectrum Disorders
GMFCS	Gross Motor Function Classification System
HIV	Human Immunodeficiency Virus
ICF-CY	International Classification of Functioning, Disability and Health, Child / Youth version
ID	Intellectual Disability
IECD	Inclusive Early Childhood Development
ILAE	International League Against Epilepsy
LAMI	Low and Middle Income

LNFS	Little or No Functional Speech
MA	Mental Age
MoHSS	Ministry of Health and Social Service
NDD	Neurodevelopmental Disorders
OAEs	Oto-Acoustic Emissions
PDA	Pathological Demand Avoidance syndrome
PHC	Primary Healthcare
PwD	Person with a Disability
SES	Socio-Economic Status
SLD	Specific Learning Disability
SSA	Sub-Saharan Africa
TB	Tuberculosis
TBI	Traumatic Brain Injury
ToM	Theory of Mind
UNESCO	United Nations Educational, Scientific and Cultural Organization
WHO	World Health Organisation

GLOSSARY

Anoxia
lack of oxygen supply to bodily organs, such as the brain

Central nervous system
consists of the brain and spinal cord, with the spinal cord functioning as the channel of communication between the brain and the body. It receives sensory information, and after integration, responds accordingly

Cognitive development
process of coming to know and understand the world over time

Development
changes of adaptive nature that occur in an orderly fashion from conception to death

Developmental delay
significant lag in terms of one or more expected developmental milestones

Developmental disability
noticeable delays in one or more of the developmental domains that have proven to be lasting, and a degree of functional limitation associated with the impairment is expected to be present indefinitely

Developmental monitoring
also referred to as "developmental surveillance"; continuous activity by (mental) healthcare provider of systematically documenting child's developmental trajectory on the basis of consultations with caregiver, observations, and assessment outcomes

Developmental screening
caregiver assessment of child's development across various domains through use of screening tool and discussion of outcome with caregiver with a view to follow-up

Early childhood
the period from foetal development to around six years of age

Early childhood development
development of a young child's physical, cognitive, emotional and social aspects

Early childhood development
programme to foster young children's developmental capacities

Early childhood intervention
range of services that include enhancement of the development of young children with developmental delays and disabilities, the capabilities of their families and their inclusion in their communities

Electroencephalogram
or EEG, is a measurement of the electrical activity in the brain

Emotional development
attaining capacity to understand, express and manage emotions over time

Episodic memory
explicit memory system in the long term memory, particulars of events / personal experiences, i.e., autobiographical memories

Experience-dependent plasticity
structuring of neuronal pathways due to specific interactions with social and natural environment

Experience-expectant plasticity
neuronal pathways that are triggered to develop during the usual course of development

Expressive language
production or the use of language

Impairment
problem with functioning of physiological system or an anatomical body part, e.g. marked deviation or loss

Incidence
proportion of new persons with the condition

Inclusive early childhood development
development of physical, cognitive, emotional and social domains of young children as a collective, and therefore irrespective of individual child's developmental status

Infancy phase
the first two years of a baby's life

Habilitation
the practice of assisting children with developmental delays or disabilities to strengthen abilities, and to gain skills and knowledge

Language development
gradual process to come to understand and communicate with language

Learning
acquisition of knowledge

Learnt helplessness
the tendency of children with disabilities to doubt their own ability and subsequently rely on help from others to perform tasks or communicate on behalf of them rather than trying themselves

Maturation
the action or process of maturing

Memory
consolidation of learnt material and its retention

Neonatal phase
the first four weeks of infancy

Nystagmus
rapid involuntary movement of the eyes

Overweight
the weight-for-height ratio is significantly higher (SD1 > 2) than the WHO growth norm, and means the child is heavy in comparison to other children of her/his age

Perinatal period
is between the end of Week 22 (154 days) of gestation and a full seven days after birth

Phenotype
a comprehensive set of observable developmental and behavioural characteristics associated with a health condition

Physical development
gradual changes in body structures and body functions

Prenatal phase
the developmental stage between conception and birth

Preschool phase
also called early childhood, from approximately 03 to 06 years of age

Prevalence
proportion of all persons with the condition

Receptive language
the understanding of language

Rehabilitation
the process during which a person is assisted to regain abilities, skills and/or knowledge that was lost or compromised as a result of a change in functioning

Reliability
statistical property indicating measurement outcome is consistent over settings and continuous over time

Scaffolding
the momentary assistance a parent, caregiver or other person who is more skilled gives to a child while the latter is learning a skill or mastering a task

Semantics
the relationship between language signifiers (words, phrases, symbols) and meaning, whether lexical (dictionary) or logical (reasoning)

Sensory development
the adaptive changes of the senses over time

Severe wasting
the weight-for-height ratio is very significantly lower (SD > 3) than the WHO growth norm, and means the child is very underweight

Social development
changes over time in relatedness to others

Strabismus
direction of eye(s) either inward or outward

Stunting
the height-for-age ratio is significantly lower (SD > 2) than the WHO growth norm, and means the child is markedly shorter than other children of her/his age

Syntax
the rules and principles of a language of sentence construction

Theory of mind
the understanding that another person has mental states (feelings, thoughts or desires) different from one's own experience

Treatment gap

the number of persons with a health condition who need treatment without getting it

Underweight

the weight-for-age ratio is significantly lower (SD > 2) than the WHO growth norm, and means the child is much thinner that children of her/his age

Validity

statistical property indicating measurement tool is true to the purpose it is being used for

Wasting

the weight-for-height ratio is significantly lower (SD > 2) than the WHO growth norm, and means the child is underweight

1 INTRODUCTION

Early Childhood Interventions probably have the biggest impact. This is true for two reasons. First, studies have shown that gains in functional capacity can be largest when interventions occur early in a child's development. Second, because if barriers are removed earlier in life there is less of a compounding effect of the multiple barriers that disabled people face.

The target group for this training module on developmental delays and disabilities is professional stakeholders in the multidisciplinary field of early identification and intervention of developmental delays and disabilities. Of specific importance is the range of service providers involved with Early Childhood Development (ECD) and Early Childhood Intervention (ECI).

Figure 1: Stakeholders associated with developmental delays and disabilities

According to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (2007), early identification and intervention, as well as the minimisation and prevention of secondary disability should be promoted (Art 25(b)). Intervention services with a view to optimal enjoyment of a meaningful life (Art 26) have to:

- start as early as possible (s1(a));
- be available in as close proximity as possible to communities in need (s1(b)); and
- provide access to the necessary assistive devices and technologies required (s3).

Specific attention is devoted to three neurodevelopmental disabilities – Intellectual Disability (ID), Autism Spectrum Conditions (ASC) and Cerebral Palsy (CP). Children on the autism spectrum and with other neurodevelopmental disabilities are neglected in terms of service delivery in Sub-Saharan Africa. One of the reasons for late identification and intervention is limited awareness and a lack of knowledge on ASC among healthcare service providers. However, early identification of and early intervention for developmental disabilities, including ASC, have to be prioritized.

- During the first six years of development, the brain is particularly responsive to opportunities to develop language and social skills;
- Parents and/or caregivers are already equipped with knowledge and skills while their child is still young;
- Early detection creates an opportunity to monitor the child for associated health conditions, and observe her/his context for barriers to favourable adjustment;
- Intervention of a high standard is associated with advances in terms of cognitive, language and social development, and adjustment; and
- Quality intervention at an early age also curbs future expenditure on education and training, living and employment.

The references at the end of this manual provide supplementary reading information on developmental delays and disabilities. These case studies can be used as a basis for discussion to review and practically apply concepts being taught from the module.

It is suggested that the manual is used in conjunction with the following manuals:

Manual 1	Understanding child disability rights
Manual 2	Early Childhood Development
Manual 4	Introduction to the International Classification of Functioning, Disability and Health: Children & Youth version (ICF-CY)

2 OVERVIEW

Developmental disability is an umbrella term for all disabilities that start during the formative years, i.e., the years of incomplete development.

The biopsychosocial model of disability creates a space for service providers from both medical and social disciplines to collaborate, and serves as the vantage point of this module. Although selected specific general abbreviations according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) are retained for ease of reference, the medical term 'disorder' is substituted with (health) condition, or preference given to the descriptor disability.

According to the UNCRPD, persons with disabilities are:

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.

According to the International Classification of Functioning, Disability and Health, Child & Youth version (ICF-CY), disability is defined as:

...the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives. Because of this relationship, different environments may have a very different impact on the same individual with a given health condition.

In keeping with the UNCRPD definition of disability, the term impairment is used in this module.

Impairments are problems in body functions or structure such as a significant deviation or loss. Body functions refer to the functioning of physiological systems and body structure to anatomical body parts.

3 DEVELOPMENTAL DELAYS

The human life cycle unfolds according to **developmental milestones**. Developmental milestones are things most children can do by a certain age.

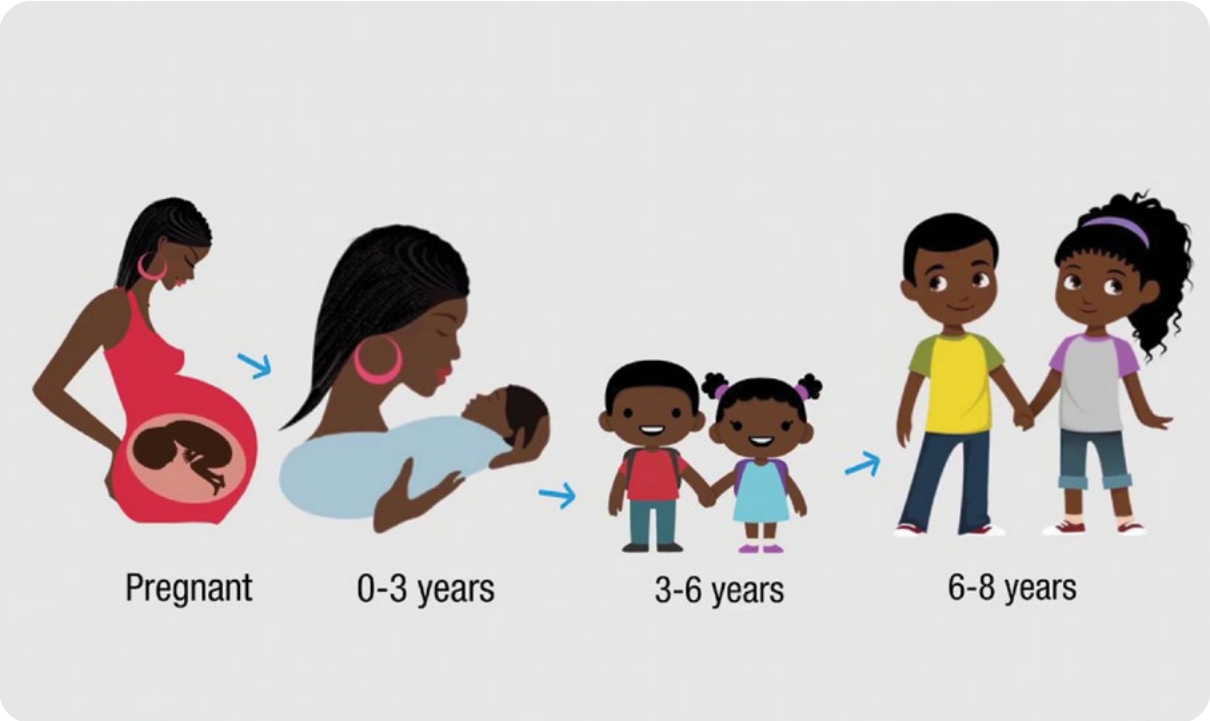
When a child is slow to achieve one or more of the milestones compared to their peers, this is known as a **developmental delay.**

The domains of motor, language and communication, and social development are generally monitored in terms of markers during early childhood. For example, when a two-year-old does not communicate or interact with attachment figures and peers, this is considered a significant delay regarding communication and social development for this age group.

An **age equivalent** is used to measure the functioning of the child in comparison to an age norm, which is the age level at which the average person in the population performs the same as the individual who is being assessed. The magnitude of the delay is revealed by comparing the age equivalent to the child's chronological age, and can be expressed as mild, moderate and severe. While an age equivalent is useful to express the measure of delay, there are also caveats in terms of application.

- The child may fall behind in one developmental domain, but not in others. It follows that the age equivalent only applies to the specific developmental area that was assessed.
- The younger the child, the less certainty exists whether the developmental delay will continue. Therefore, besides being applicable to a specific aspect of development, the validity of the age equivalent is of limited duration as well. A conclusion with regard to the extent of the delay should therefore only be made after very young children have received suitable intervention.
- Due to a raw score that is linked to a chronological age, it can be misinterpreted from a developmental perspective.

(S)cale scores are unequal. 'One year's growth' has a very different meaning at different points in the age continuum and for different areas of adaptive behavior. For instance, children acquire communication skills more rapidly between the ages of 2 and 3 than between the ages of 10 and 11; thus a 3-year-old who obtains an age equivalent of 2 years is further behind his or her age mates than is an 11-year-old who obtains an age equivalent of 10. (Sparrow et al 2005: 65)



Any child is a **'developmental being.'** In the case of a child with severe delays, the process of maturation should be individualised.

There are different reasons for delays in development. Complications, trauma and injury before, during or after birth, and life-threatening illnesses or serious accidents can be related to marked disruption in development. Delays can also be the result of external circumstances such as poverty and the knock-on effect on development in the early years. The effect of child maltreatment should also not be underestimated.

'Mental age' is a specific age equivalent that is generally used in relation to development. During the period of intellectual development (usually between birth to approximately 17 years of age), the individual's mental age (MA) and chronological age (CA) correspond. Mental age is seen to reflect a child's overall level of intellectual development.

As children grow older, their intelligence increases with respect to their ability to perform intellectual tasks of increasing difficulty and to perform them faster. Although this construct of mental age is well-known, it should be used with caution. The synonymous term **'test age'** should rather be used. Test age refers to the match between the test taker's raw score and the chronological age attainment with which this score is associated.

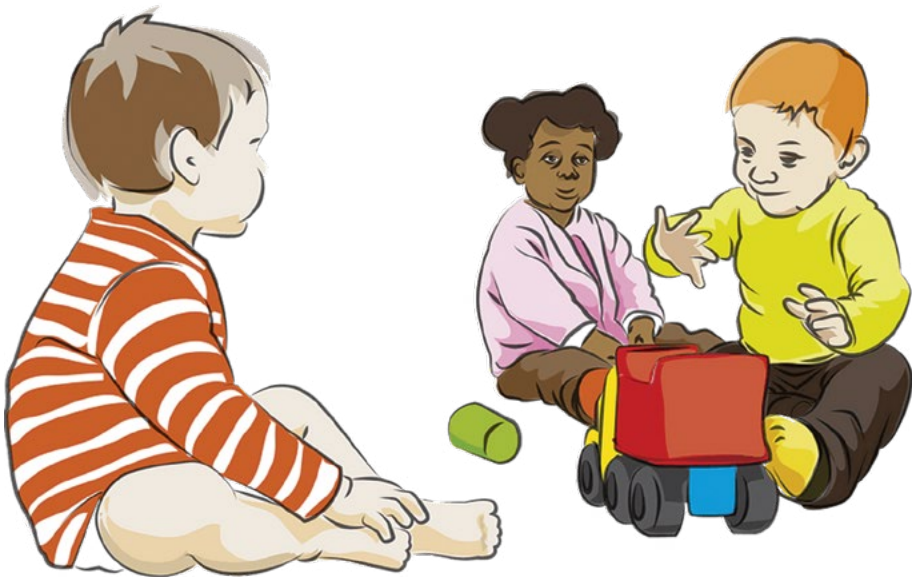
Age equivalent

This comparison to a triathlete is used to clarify an age equivalent as domain specific:

Our hypothetical triathlete answers the question [of where he stands relative to his peer group] by comparing his speeds with others' documented speeds or by actually entering a competition. This is where he learns where he stands in the pack. Could it be that his slowest run is fast enough to win that segment of the competition? Or is it possible that his fastest swim doesn't even qualify to enter? For the child, the question then concerns his or her development in each domain relative to age-specific norms.

Some children's delays are temporary and they catch up with their peers. However, other children do not and at some point reach a 'developmental ceiling.' They consequently remain behind their age group. For example, cerebral palsy (CP) is associated with specific motor developmental milestones that will not be attained, rather than attained later than the expectation.

The age of five years is a significant developmental marker in children Substantial deviation from the expected developmental course after five years of age, is no longer considered to be an indication of a delay, but rather as a developmental disability. Moreover, the category **Global Developmental Delay** is reserved for pre-schoolers younger than five years of age. This refers to them not meeting expectations on a number of developmental milestones while they are too young for assessment or, where the severity of delays renders formal assessment impossible.



4 DEVELOPMENTAL DISABILITIES

When developmental delays have proven to be long-term, and are expected to continue throughout the individual's lifetime, it is described as a **developmental disability.**

Developmental disabilities are often already recognisable in one or more aspect of daily functioning during early childhood or by the time the child enters school. However, most developmental disabilities cannot simply be explained by the 'incomplete' development of specific domains. The neurodivergent nature of these disabilities should also be understood. The development of children with developmental disabilities is complex because – in contrast to neurotypical children – it is compromised by varied brain development.

Differing from the developmental norm should thus not simply be considered as 'lagging.' Features may vary as a result of diverse structural and/or functional neurological systems and their interaction. A pertinent example is Autism Spectrum.

There are different causes of developmental disability. Most developmental disabilities are congenital (biological origin before or during birth), but some happen at a later stage as a result of a health condition, injury, or exposure to toxins. For example, duplication of chromosome 21 during cell differentiation is linked to Down Syndrome. Premature birth and/or low birth weight hold a significant risk for neurodevelopmental conditions. Other congenital disabilities are cleft palate and club foot. Anoxia (no oxygen) and probably hypoxia (interrupted oxygen flow) during birthcause damage to the brain and therefore neurodevelopmental conditions. Illnesses such as jaundice left untreated, meningitis and measles are linked to developmental hearing impairment. Traumatic brain injury is associated with cognitive impairment.

The impact of the disability can be specific, for example in terms of scholastic skills development or pervasive, for example general cognitive impairment. A relevant factor with regard to its impact on brain growth is the sleeper effect: children can 'grow into deficit.'

The developmental disability may only become apparent when neurological functions that had not developed are expected to come online at a later stage. For example, the effects of premature birth or birth trauma are only recognised at school-going age when **Specific Learning Disability (SLD)** poses a major challenge in the mastery of learning the basic scholastic skills (reading, spelling, writing and maths).

Screening for neurodevelopmental delays at immunization clinics in Lagos State, Nigeria, 0,9% infants between the ages of three and 36 months were found to be developmentally delayed. These neurodevelopmental delays were proportionately linked to nutritional deficiencies (18,5%), delays of a non-specific nature associated with epilepsy (25,9%), and the following developmental disabilities: Cerebral Palsy (33,3%), Autism Spectrum Disorder (features) (14,8%), and Down Syndrome (7,4%).

4.1 Intellectual Disability (ID)

The 'developmental-versus-difference'[1] question has not yet been resolved in relation to children with intellectual delays and disabilities.

Do all children – regardless of intellectual impairments – progress through the same developmental milestones in a similar sequence, but at different rates? Or does the development of children with mental 'disability' proceed in a different, less sequential, and less organized fashion? (Mash & Wolfe 2010: 280)

In comparison to typically developing children, some children s show slower progress through the developmental stages, soon reaching a developmental ceiling. In others, neurodiverse cognitive development is explained in terms of the effect of organic impairments (e.g. chromosomal anomalies such as Down Syndrome), over and above the features associated with the first group.

There are general developmental features associated with cognitive delays and disabilities.

4.1.1 Motor development

Attaining motor developmental milestones (i.e., sitting, crawling and walking at the expected age) is generally inversely related to the level of severity of the disability. Therefore, the more pronounced the cognitive disability, the later the child usually reaches the respective milestones.

Slow, uncoordinated and clumsy gross movement may occur, and it is helpful to scaffold the child's mastery of fine motor movements. The way in which complex motor skills are performed at each developmental stage is evidence of the extent of the developmental delays experienced. These motor difficulties can be improved by appropriate intervention.

4.1.2 Perceptual development

The perception of children with cognitive disability tends to be of a more cursory and superficial nature. Due to lags in sensory awareness, perceptual details may be missed due to immature development of the faculties of visual, auditory and tactile discrimination. In addition, if neurological dysfunction is associated with the sensory areas, perceptual dysfunction will be even more compromised.

4.1.3 Cognitive development

The development of cognitive proficiency is described as 'a reduced ability to learn.' The pace of cognitive development tends to be markedly slower for children with ID due to inefficient information processing. Related to cognitive inflexibility, cognitive actions can be indiscriminately repeated irrespective of the demands of the situation. Knowledge, or an insight learnt from one situation, is not applied in a different context, known as generalisation. Children with cognitive disability are often distractible, that is, they find it difficult to ignore irrelevant stimuli in their learning environment, and can be challenged to maintain their focus on the task at hand. Attention span is usually short. The attentional capacity of children with ID can be enhanced by utilising visual information during cognitive activities.

Children with certain health conditions, for example hydrocephalus, have slower cognitive processing and working memory limitations are common. For example, a child may not be able to give an answer to the question, "In what way are an apple and grapes alike?" Her/his inability to give an answer may not be as a result of not knowing that both are fruit, but due to the cognitive effort it takes to keep the verbal concepts ("apple" and "grapes") in mind.

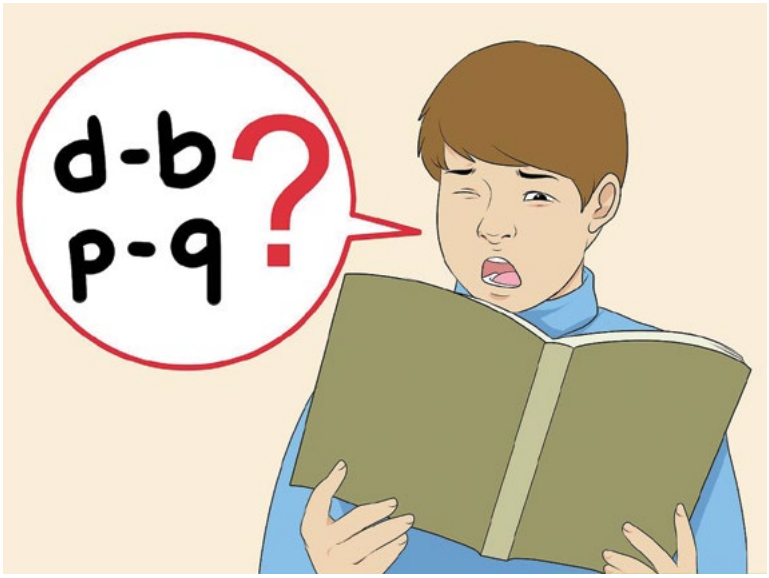
It is recommended that a passive, rather than spontaneous, approach to learning strategies is applied in these cases.

It takes time for children with cognitive challenges to store information in long-term memory but once stored, retention equals that of children without significant challenges. However, children with ID will generally struggle to access and retrieve this information from their memory.

Due to poor organisational strategies, children with ID can become confused when new information is introduced during recall of learnt information. Also, more recent information (a 'new' memory) is harder to recall than less recent information (an 'old' memory). Generalised memory problems are common. When specific brain structures related to memory are damaged or become dysfunctional as part of a specific condition, the impairment will be specific. For example, children with epilepsy tend to have difficulty with verbal memory (to recall spoken information).

4.1.4 Language development

Command of language equips children with a 'tool' for reasoning. There is a significant positive correlation between the developmental domains of language and cognition. As with motor development, children with marked cognitive developmental delays usually attain the milestones of language development at a slower pace than typically developing children. However, quantitative and qualitative differences[2] frequently remain even if the norm group for comparison is selected on the basis of an age equivalent.[3]



Dysfunctional speech development is more prevalent among children with severe ID. Little or no functional speech (LNFS) also occurs at a higher frequency.

4.1.5 Emotional development

Children with developmental disabilities tend to be sensitive to stress and anxiety, and sometimes display extreme emotional fluctuations. Due to a generally lower resistance to stress, they might become easily unsettled or upset about seemingly minor things. Acting-out behaviour in the form of temper tantrums[4] and/or meltdowns[5] are inappropriately used for emotional communication.

Learned helplessness can also develop over time due to their experience of rejection, failure and unfavourable interpersonal interactions. Learnt helplessness means the tendency to doubt their own ability and subsequently seek help from others to perform tasks rather than trying themselves. They grow dependent on others even if they are able to manage on their own, and this has a negative effect on developing perseverance.

The actual competency of children with cognitive disability can be underestimated due to the dynamics of these emotional factors, and they may also have a negative impact on their overall assessment.

Table 1: Descriptive profile of ID

BIOLOGICAL		Stage
Prenatal, e.g. genetic conditions Perinatal, e.g. premature birth or birth complications like anoxia Postnatal, e.g. meningitis[6] or traumatic brain injury (para 4.6)	CAUSE	Familial cognitive disability Environmental deprivation
Moderate, severe or profound ID		Mild ID
Approximately equal prevalence across population and SES groups More often also other physical disabilities	ASSOCIATED FEATURES	Higher in minority and low socio-economic status (SES) groups

The term **'learning difficulties'** should not be used in reference to intellectual disability. In the British education system 'learning difficulties' refers to cognitive limitations and therefore also includes ID, but this terminology is not aligned to international classification convention. A pattern of difficulties in learning is related to **Specific Learning Disability (SLD)**, i.e., challenges related to the scholastic skills: reading, spelling, writing and maths.

ID was previously known as "mental retardation". Due to the offensive connotation of this label in the social context, it should no longer be used. Moreover, the change in terminology is a progression in understanding the human phenomenon of disability as influenced by the International Classification of Functioning, Disability and Health. (WHO 2001)

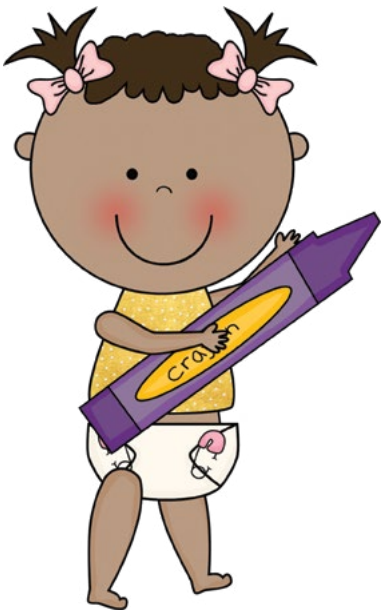
In a most cases, the cause of ID cannot be specifically identified. Its basis however, can be located in two areas: biology and contextual factors such as poverty and inadequate education play a decisive role in cognitive development. (Table 1)

Intellectual disability is charaterised by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

The five assumptions that supplement this definition are:

- The child's peers and culture provide the context for interpreting limitations to present functioning.
- During assessment, consideration is given to cultural and linguistic diversity and variation in terms of communication, behaviour as well as sensory and motor development.
- The individual has limitations, but also strengths.
- A profile of required support is established, taking the child's limitations into consideration.
- The functioning of the child with ID will be enhanced by receiving continuous individualised support.

Intelligence – which refers to an individual's ability to learn – is a function of cognition. Although traditional intelligence tests are frequently administered to quantify intellectual functioning, it is advisable to follow a dynamic approach to testing. During dynamic assessment a learning situation is created, in order to evaluate the child's potential to benefit from learning. Learning potential is complementary to adaptability.



Infant intelligence testing has low predictive value with regard to future intellectual functioning. Its projective significance is only valid from the age of five years onwards. Different factors account for this.

1. The nature of development is more heterogeneous than what is commonly believed - the variation among very young children of the same chronological age has to be taken into account.

2. The constructs that are being measured are different for infants versus older children: for infants the emphasis is on motor development and sociability, whereas for the older group test items are more related to scholastic functioning.

3. The interaction between brain plasticity and opportunities for learning also play a role - intellectual functioning is impacted by the home environment and socioeconomic status (SES).

Conversely, *"(in) cases where infants are neurologically impaired and function considerably below average, there is a greater degree of continuity (and therefore greater predictability) between functioning in infancy and childhood, due to the biological constraints on development."* (Roodt et al 2009: 239-240)

Using information processing models for infant intelligence testing has superior predictive validity than traditional tests. The definition of intelligence according to compliments information processing theories.

Intelligence is composed of three components. The first is **attentional processes**, which provide focused cognitive activity, the second is **information processes** of two types (simultaneous and successive); and the third is **planning processes**, which provide (a) the control of attention; (b) the use of information processes, internal and external knowledge, and cognitive tools; and (c) overall self-regulation to achieve a desired goal.

Static vs dynamic testing

A static or a dynamic approach can be taken to testing intellectual functioning.

Conventional determination of intellectual ability (IQ testing) assumes that what a child knows at the point of testing is a reliable prediction of the knowledge she or he will have some time in future. (Borkowski et al 2009: 265)

When psychometric tests are administered to determine intellectual ability, the procedure is product-based in the sense that the highly complex and unique cognitive functioning of an individual is reduced to a fixed score, the IQ (intelligence quotient). Furthermore, an obtained IQ score is limited to the learning areas included in the compilation of the test.

Alternatively, the process-oriented approach to intelligence places emphasis on learning potential embedded in a cultural context and assessment is conducted in a dynamic way. The child's abilities and limitations are evaluated while considering the learning context.

> Dynamic assessment is a specific approach to assessment which incorporates training into the assessment process in an attempt to evaluate not only the current level of cognitive ability, but also the potential future level of ability. (Van Eeden & De Beer 2000: 131)

When opportunity for learning precedes assessment, factors that can affect performance are equalised. Dynamic assessment caters to the potential effect of learning on output, by including a learning experience. Assessing learning potential is particularly useful in contexts associated with insufficient opportunities for learning related to SES and education. Moreover, the competence of children with developmental challenges can be underestimated, unless they are assessed only after they have had assistance and adequate support to learn what is expected of them.

Adaptive behaviour is defined as the performance of daily activities required for personal and social sufficiency.

The following four principles apply:

- Adaptive functioning is relative to chronological age.
- It depends on cultural expectations and standards.
- Adaptive behaviour is modifiable by various factors.
- The emphasis is placed on using the ability adaptively, rather than merely "owning" an ability.

Adaptive reasoning is required for three essential life domains:

1. The conceptual or academic domain is related to competencies such as memory, language, scholastic skills, knowledge acquisition and reasoning.
2. The social domain is associated with relatedness, for example interpersonal relationships, prosocial (to the benefit of others) emotion and communication skills.
3. The practical domain involves learning, self-sufficiency and competency across various life settings such as home, school, work and community.

Mental age

The development of a child with a mental age of ten years corresponds to the mental development of the average ten-year-old child, no matter what his/her chronological age is.

While determining an equivalent 'mental age' for an adult with ID may be quite useful to describe their level of cognitive development and capacity to learn, it is also understood that a person's mental age does not simply mean he or she has the mind of a younger person.

This term is considered a patronising misnomer – the life experience of the individual is not reflected in any way, and for the misinformed its use can violate the dignity of persons with ID. For example, in *State v Denga* (South African Criminal Law Case number 43.411.12B), the evidence of two adolescent boys of respectively 17 and 18 years turned into a credibility issue, because their mental ages and their sexual knowledge were not considered to be compatible.

A 2003 research study on recall accuracy of children with ID further demonstrates the necessity for caution when applying the concept of mental age. The experimental group (participants

with ID) recalled a higher frequency of accurate information during free recall in comparison to the control group, matched on mental age (MA). Conversely, the same experimental group made changes to their answers more often during a repeated recall condition than the MA control group. The effect of cognitive disability on developmental attainments can therefore not be generalised. Children with disabilities do not simply share all characteristics with their mental age counterparts. Mental age cannot be considered as a perfect measure of cognitive functioning due to the role of affective and motivational factors during the performance of children with cognitive impairments.

ID is classified according to severity: mild, moderate, severe or profound. In Table 2, the four levels of severity are reflected according to the three domains of adaptive behaviour (practical, social and conceptual) at four years of age. Besides the developmental difference distinguished among levels, the subtle variance within a level is also presented, with a description of behaviour associated with the 50th and 85th percentile[7] respectively.

The developmental functioning of two groups of four-year-olds with ID at specific levels of severity are compared:

The group with 50% (relatively 'less' adaptive behaviour) is compared to the group with 85% (relatively "more" adaptive behaviour) in terms of the degree of severity of ID.

More important than an individual's cognitive impairment is her/his adaptive functioning. If a discrepancy exists between intellectual (criterion 1) and adaptive (criterion 2) functioning, the latter will guide the classification of severity. The acquisition of adaptive skills does not only rely on ability, but also on experience and opportunity. For example, the 'instability' of identifying mild ID is exposed when children who were initially categorised with mild ID later function without ID as adults. Detection of severe and profound ID is more stable though.

ID is one of the invisible developmental disabilities, especially when the degree of cognitive impairment is mild. Due to no apparent physical or tangible cues suggesting varied development (for example the facial features of Down Syndrome or AAC technology for a nonverbal child to communicate), children with ID are sometimes simply labelled lazy or 'stupid', without any regard for the impact of the impairment on the ability to learn. Early identification is critical for learners with mild ID to develop their potential. Unfortunately this does not happen frequently. In most cases, mild ID is only identified later than six years of age, when the child enters formal education.

Table 2: Intellectual Disability levels: Adaptive behaviour at the age of 4 years

MILD	MODERATE	SEVERE	PROFOUND
85TH PERCENTILE			
Jumps up with both feet from floor at once	Jumps up with both feet from floor at once	Walks up / down the stairs, with alternate feet	Walks about 1,5 metres
Flushes toilet after use	Flushes toilet after use	Goes to bathroom on reminder	Eliminates when on toilet
Puts shoes on correct feet	Puts shoes on correct feet	Puts toothbrush in mouth; begins brushing motion	Extends / withdraws arms / legs when being un/dressed
Eats in public while supervised, no attention to eating behaviour	Eats in public while supervised, no attention to eating behaviour	Eats in public while supervised, no attention to eating behaviour	Drinks without spilling from glass / cup with assistance
Names 10 common objects when prompted	Names 10 common objects when prompted	Says / signs yes/no in response to question, e.g. "Do you want to go out and play?"	Follows simple instruction, e.g. "Come here!"
Makes circles / lines on chalkboard / piece of paper	Makes circles / lines on chalkboard / piece of paper	Turns pages in book one by one	Scribbles with crayon / chalk / pencil
Sorts coins from other small metal objects	Separates one object from group upon request, "Give me one …"	Separates one object from group upon request, "Give me one …"	Does not separate one object from group upon request, "Give me one …"
Goes to public places supervised without drawing unfavourable attention to behaviour	Goes to public places supervised without drawing unfavourable attention to behaviour	Goes to public places supervised without drawing unfavourable attention to behaviour	Participates in single activity for 10 mins when not interrupted
50TH PERCENTILE			
Runs	Runs	Walks up / down the stairs, putting both feet on each step	Does not sit without support
Bowel control	Goes to toilet after reminder	Eliminates when on toilet	Does not eliminate when on toilet
Puts toothbrush in mouth; begins brushing motion	Removes pullover	Extends / withdraws arms / legs while being un/dressed	Does not extend / withdraw arms / legs while being un/dressed
Eats full meal – little / no spilling	Eats full meal – little / no spilling	Uses spoon for picking up food and eating	Does not drink without spilling from glass / cup with assistance
Says or signs yes/no in response to question, e.g. "Do you want to go out and play?"	Stops activity when requested with "Stop!" / "no!"	Follows simple instruction, e.g. "Come here!"	Does not follow simple instruction, e.g. "Come here!"
Turns pages in book one by one	Turns pages in book one by one	Scribbles with crayon / chalk / pencil	Does not scribble with crayon / chalk / pencil
Separates one object from group upon request, "Give me one …"	Separates one object from group upon request, "Give me one …"	Does not separate one object from group upon request, "Give me one …"	Does not separate one object from group upon request, "Give me one …"
Participates in single activity for 10 mins when not interrupted	Participates in single activity for 10 mins when not interrupted	Does not participate in single activity for 10 mins when not interrupted	Does not participate in single activity for 10 mins when not interrupted

4.2 Autism

Autism is a biologically based lifelong developmental disability that is present in the first few years of life.

Various terminologies for conditions related to autism have been used over the years,[8] and are currently all grouped together on the autism spectrum as Autism Spectrum Disorder (ASD), according to the DSM-5. The tendency is to refer to spectrum 'conditions' (plural), in order to acknowledge that definite subtypes that exis. The related term is Autism Spectrum Conditions or ASC.

Although autism can be identified in children as young as two years, more often it is only identified at a later age due to its association with learning difficulties.

There are some early signs during the preschool years that may point to neurodivergent development:

- lack of or delayed need to gain attention and express interest in something;
- repetitive behaviours, e.g. repeating the same play sequence without variation;
- resistance to change in or variation of routine;
- growing challenges regarding social interaction and social communication; and
- behavioural actions such as pinching, biting, kicking, self-injury or pica.[9]

It is thought that one in every three pre-schoolers with autism has sleeping difficulties.

Pathological Demand Avoidance (PDA)

Children with PDA share the same areas of difficulty as those with other types of autism spectrum disorder (including sensory problems); however the central difficulty is the child's need to avoid everyday demands and expectations. This extreme avoidance stems from an anxiety-led need to be in control. Children with PDA appear to have better social understanding and communication than others on the spectrum. Some children use distraction or withdrawal to avoid a demand, however many children can exhibit extreme and sometimes violent meltdowns when asked to do simple things, e.g., 'put your coat on.'

ASD is diagnosed according to four criteria:

- Functioning related to social communication and interpersonal interaction displays significant variation from expectations in more than one context.
- Personal interests and/or behaviour patterns are limited and of stereotypical nature.
- Symptoms are already present during the associated developmental stage, including early childhood, although possibly only recognised at a later stage.
- Marked restrictions in the domains of adaptive functioning, e.g., socialisation and/or education.

Girls are less likely than boys to be identified with autism.

ASC and gender difference

Despite the current progression in awareness of ASC, gender differences have only recently become the focus of research. Amongst topical research, 'camouflaging' is a common theme in females, elucidating why females with ASC are more vulnerable to being overlooked in education. Camouflaging can be divided into three categories: assimilation, compensation and masking.

Typically, males display decreased functional social conduct and more repetitive acts than females. Whilst these characteristics relate to the ASC triad of impairments that most educators are aware of, females 'camouflage' these struggles due to lack of educator awareness and understanding.

Because females exhibit less stereotypical characteristics of ASC than males, they are less likely to be diagnosed. Emotional and behavioural issues are a more appropriate indicator of ASC in females in comparison to the more constricted and repetitive behaviours that are typically seen in males. Consequently, educator focus on the commonly perceived male characteristics of ASC may result in the neglect of females who do not adhere to predetermined categories.

ASD is associated with multiple causes, but research in this regard points to genetically-based neurobiological conditions. Significant prevalence of ID (and/or epilepsy is linked with ASD). Autism is associated with a neurodevelopmental profile. characteristic features of ASD show up in various combinations and degrees of severity. Adaptive behaviour also presents on a continuum. (Figure 2)

The three critical factors for adjustment in the context of the child with ASD are:

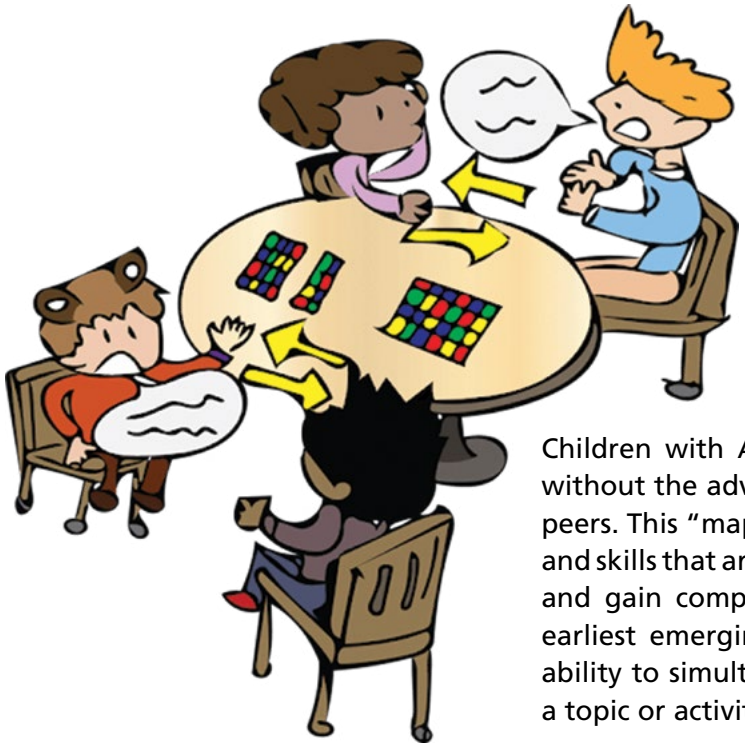
level of cognitive functioning,

extent of language difficulties, and

potential to develop adaptive behaviour.

Intellectually, children with ASD can function in the full range between superior and severe impairment. In terms of language, children with ASD also vary – from having no expressive language to having sufficient communication skills. Their adaptive behaviour also differs - there is an association between gains in adjustment and cognitive functioning. Children with ASD have not 'lost touch' with objective reality. It is the degree of neurodevelopmental variation that determines the extent of participation in social reality.

Figure 2: ASD continuum of adaptive functioning



Children with ASD negotiate through a social world without the advantage of the "intuitive map" of their peers. This "map" is comprised of many social concepts and skills that are present early in a child's development, and gain complexity as a child matures. One of the earliest emerging social skills is joint attention - the ability to simultaneously focus and share attention on a topic or activity with another person.

At pre-school stage, children can make complex inferences about the mental states of others, referred to in the literature as **Theory of Mind (ToM).** This, along with other cognitive and social communication skills, enables a child to empathize with others, understand the need to take turns, predict even novel social sequences, and to appreciate what it means to be part of a social group.

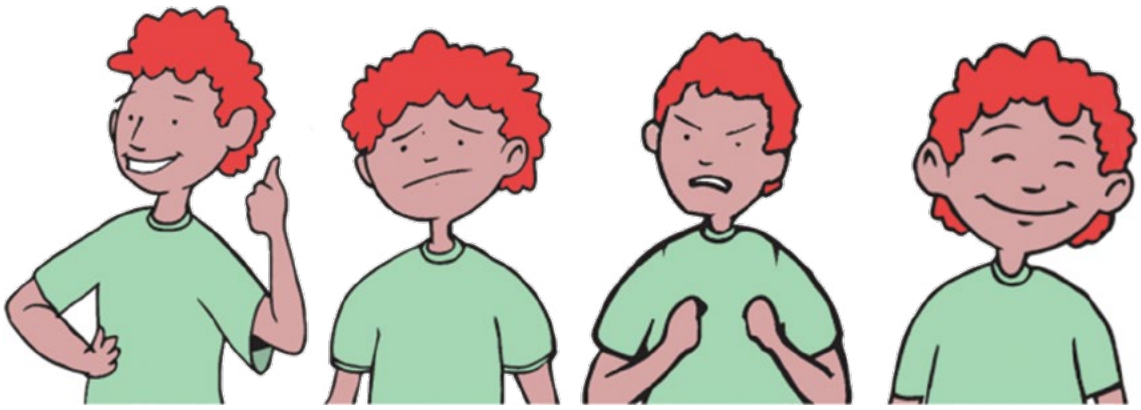
A 'triad of impairments' - social functioning, communication and behavioural repertoire are typical of children with ASD and they are prone to bullying by their peers as a result of this.

4.2.1 Social challenges

Irrespective of probable cognitive challenges, children with ASD have major difficulties regarding general psychosocial functioning, and in particular reciprocal social interaction. Their ability to process interpersonal information is restricted. For example, facial recognition and interpretation of facial expression, and particularly fear, pose a marked challenge. While some children are simply disinterested in socialising, others may turn to feeling threatened during social interaction due to, inter alia, a limited ability to read social cues, as well as restricted understanding of the essentials of relatedness (reciprocity, sharing behaviour and enjoyment) and social conventions. Absence of joint attention, i.e. the ability to coordinate attention to a social partner and an object or event of mutual interest is an early indication used for screening of infants. (Table 3)

Compared to neurotypical children, children with ASD usually do not spontaneously exhibit nonverbal expression of emotion. However, when emotional expression does occur, it often happens in unusual ways. For example, expressions of anxiety may be misread as aggressive behaviour to the untrained eye.

Autism, more than any other clinical condition, highlights the important linkage between language and social interaction and how these critical developmental processes may be negatively affected by perturbations of neurodevelopment. Knowledge of the normal developmental context is necessary to best appreciate the complexities of associated neural and behavioral deficits in AD (Autistic Disorder). Unlike the social milestones in the earliest formative years, the child with incipient AD follows a subtly atypical developmental course that warns of the difficulties to come.



4.2.2 Communication difficulties

Atypical language development is a telling feature of children with ASD. It is in the stage of preverbal communication – during which nonverbal language precedes the use of actual words for communication – that they already distinguish themselves from neurotypical children or other forms of developmental disability. Even though the language development of children with ASD often follows the expected course until the age of approximately two years, many then 'lose' some of their ability to communicate. Children who do develop language typically do so before the age of five years. Language acquisition of infants and pre-schoolers with ASD is complimented by maternal synchronization. This means that the language gains of the young child are directly related to the mother's measure of attunement to her/his social-pragmatic cues (attention, activity and communication).

Sensory dominance is the tendency to focus on certain types of sensory input over others – for example, a preference for sight over sound. Stimulus overselectivity is the tendency to focus on one feature of an object or event while ignoring other equally important features. (Mash & Wolfe 2010: 311)

ASC Neurodevelopmental profile

- **Sensory processing**

Children with autism have 'tunnel vision' and/or 'tunnel hearing' due to the challenges created by dysfunctional sensory processing.

Elevated levels of generalised anxiety are commonly caused by sensory processing difficulties.

- **Cognitive processing**

A range of neurocognitive deficiencies are associated with ASC that results in 'uneven' cognitive profiles of individuals. Individual children differ in terms of their relative strengths and weaknesses.

Children with autism can experience major attentional difficulties. Moreover, a significant challenge during information processing relates to central incoherence. Information is processed in a fragmented way, without taking the relationship of the parts to the whole into account ie. the bigger picture.

Context blindness means interconnecting variables are not considered throughout the thinking process and this is causally linked to a heightened level of anxiety.

Table 3: Neurodevelopmental aspects of early communication

ASPECT	FUNCTION
Mutual gaze	Establishing intersubjective connection[10]
Shared gaze	Establishing joint attention to something else
Pointing / showing	Sharing interest in objects / activities
Vocalising	Gaining attention
Responding to name	Recognising the self
Attending to caregiver's voice	Acknowledging the other
Showing interest in children / persons	Orienting self for shared "minds"
Pretend play	Representing objects, actions and characters for meaning making

A significant portion of children with ASD remain nonverbal and do not develop speech at all. With regard to the verbal group, expressive language is usually more developed in comparison to receptive language.[11] Further, when children develop a sufficient command of formal language[12] usually after a delay, they tend to be unspontaneous communicators. Intonation and rhythm can be peculiar, and unusual language is often employed, including: pronoun reversals,[13] echolalia,[14] perseverative speech,[15] neologisms,[16] private metaphors,[17] gestalt phrases,[18] scripts,[19] and idiosyncratic use of words.

Children with autism prefer to communicate through behaviour rather than verbalisation for social communication. The pragmatic use of language poses a marked stumbling block due to the inability to decode the social context in which communication takes place. As a result, the gist of a conversation, humour, sarcasm, irony and figures of speech are beyond comprehension.

Discrepancies regarding command of language can be striking. For example, some children may be unable to ask for assistance when needed, despite having above average language skills. In fact, children with autism have to be taught that questions are asked with a view to obtain (sometimes very useful) information. The verbosity of some children with autism conceals verbal difficulties and their communicative capabilities may subsequently be overestimated. The array of speech and language problems associated with ASC is addressed by means of augmentative and alternative communication (AAC).

4.2.3 Repetitive behaviour and narrow interests

Children with autism are often exceptionally routinized due to a need for consistency in their environment. Rules have to be rigidly obeyed. Self-stimulatory behaviour[20] is employed to cope with sensory overload in an overstimulating setting. Self-stimulation is sensory in nature, repetitive and executed in a stereotypical fashion. Stereotypical body movements often reveal uncertainty about situational expectations.

It is not only children on the autism spectrum who display hyper- or hypo-reactivity to sensory input. However, as a result of its prevalence in the ASC group, atypical sensory behaviour is

> Herein lies the paradox when dealing with epilepsy in autism; it appears early and often remains concealed during the early stages of development. (Lamb et al 2019: 2, 5)

seen as a significant marker. These children are generally known to be picky eaters due to sensitivities related to food textures. Other examples are sensitivity to sound or insensitivity to pain.

Children display narrow interests, and can develop a preoccupation with specific topics.[21] The level of activities of a child in the ASC group, while in pursuit of a unique single interest, frequently exceeds developmental expectations, and so can be misleading.[22]

The association between autism and epilepsy should not go undetected. In fact, having an epileptic seizure may be misinterpreted as ASC associated behaviour (stereotypes). Early identification is crucial so as to provide appropriate and timely treatment.

In Sub-Saharan Africa a clear link between ASD and ID has been noted. There also seems to be a higher prevalence of nonverbal ASD[23] and a lower frequency of repetitive behaviours by comparison. It has also been noted that when parents or caregivers point out symptomatic behaviour of their children, they usually do not relate typical features. They mostly rather convey distressful conduct such as sensory difficulties, impulsivity, hyperactivity, self-mutilation/ self-injuriousness and aggression. Difficulty with self-regulation is also a common issue, which requires proactive early intervention.

ASD in Africa

The onset of ASD symptoms among African children, aged under five (and often 3 years old) coincides with a time period in which these children are vulnerable to physical illness and infectious diseases associated with neurological consequences. There is an over-representation of non-verbal cases of ASD among African children. The lack of, or limited, expressive language ability could be related to late interventions, resulting from late presentation and identification.

In Africa, it has been observed that ASD is rarely diagnosed exclusively of intellectual disabilities and there is a wide gap between age of onset of symptoms and diagnosis of ASD. Therefore, identification and diagnosis of ASD has been observed to be late among African children. Possible factors identified from the literature, that are associated with late identification of ASD in Africa include: poor knowledge and awareness about ASD; cultural beliefs and practices; tortuous pathway to care / help-seeking behavior; inadequate number of trained personnel; inadequate health-care facilities. There is a scarcity of intervention programs for children with ASD and other NDD in Africa. The few available services are very expensive with huge unaffordable cost to most of the parents of affected children.

4.3 Attentional conditions or ADHD[25]

According to the DSM-5, **Attention Deficit / Hyperactivity Disorder (ADHD)** forms part of the cluster of neurodevelopmental disabilities. ADHD has two dimensions, attention and activity and regulation. The child's functioning is markedly affected by the following behaviour patterns:

Inattention: The child has major difficulty in sustaining focus on the task at hand and as a result, gets distracted and fails to complete it properly.

Hyperactivity: The child's behaviour is characterised by motor over-activity, for example, talkativeness, continuous movement of a body part, or fiddling.

Impulsivity: Mental over-activity is present, and she or he is subsequently inclined to act overly hastily without considering potential consequences, also without regard for risk of personal harm.

ADHD has a substantial genetic link. Compared to neurotypical peers, children with ADHD display clear variation in the development of the prefrontal cortex, an area of the brain responsible for executive functioning, inter alia regulatory processes.

ADHD is usually only identified in the school-going years, because variations in motor activity before the age of four years do not always allow a distinction between behaviour still to be expected, and behaviour outside of the developmental norm. However, the precursor of ADHD is usually excessive motor activity in the preschool years. With formal school entry in mind, intervention with regards to their developing attentional and organisational skills is indicated.

While hyperactivity seems to lessen with time, inattention remains prominent during middle childhood. On the other hand, as children grow older, hyperactivity can change in manifestation, for example through restlessness, impatience or fidgetiness. Impulsivity can continue to be challenging despite reduced hyperactivity. Children with ADHD seem to be less adept at 'mind reading' due to an inverse relationship between attention and cognitive regulation, and ToM; inattention and impulsivity is related to restricted ToM skills. For some children, a limited ability to 'read between the lines' subsequently gives rise to social clumsiness.

Core and developmental engagement

In more recent developmental research, the construct **'engagement'** has emerged and is described as the amount of time a child is actively involved in social interaction with other children or adults in activities or play materials, in a developmentally and contextually appropriate manner.

With specific focus on early childhood development, two kinds of engagement are distinguished:

1. **Core engagement** is generally found among all developmental ages, and refers to basic attentional and determined behaviour.
2. Alternatively, **developmental engagement** is age related. Therefore, complex activities such as problem solving, rule-based or pretense play and social interaction requiring engagement of this kind are most often observed among older pre-schoolers. Sustained attention ('concentration'), perseverance, ability to delay gratification etc. are also associated with developmental engagement.

Although hyperactivity has an unfavourable effect on both core and developmental engagement, it seems to have a more pronounced impact on core engagement, i.e., basic attention in a social context.

4.4 Specific Learning Disability or SLD[25]

Specific Learning Disability (SLD) becomes relevant during the years of formal schooling. The general intellectual potential of children with learning difficulties usually matches or exceeds age expectations. However, their scholastic performance is not on par with intellectual competence. Various types of learning difficulties may occur as a result of compromised neurological processing of learning material, at different stages of development.

SLD applies to the mastery and use of the following academic skills: reading, reading comprehension, spelling, written expression, numeracy, and mathematical reasoning. In formal assessment, the functionality of these skills differs significantly from chronological age / grade expectations and its interference in terms of academic outcomes and/or daily living is obvious.

In contrast to talking or walking, which are acquired developmental milestones that emerge with brain maturation, academic skills (e.g., reading, spelling, writing, mathematics) have to be taught and learned explicitly. Specific learning disorder disrupts the normal pattern of learning academic skills, it is not simply a consequence of lack of opportunity for learning or inadequate instruction.

Developmental delays in language, attentional and/or motor skills in early childhood are often forerunners of SLD. Pre-schoolers may also display a negative attitude towards learning and/or oppositional behaviour.

Possible precursors in early childhood for SLD

The following behaviours can precede the emergence of SLD:

- disinterest in playing word sound games (rhyming, repeating)
- struggle to memorise nursery rhymes
- baby talk or mispronouncing words
- difficulty recalling names of letters or numbers, or days of the week
- challenges in learning to count
- effort to recognise letters of their own name
- difficulty to break down multi-syllable words into parts (phonemic awareness)
- effort with recognising rhyming words, first / last sound of word (auditory discrimination).

4.5 Cerebral palsy (CP)

Cerebral palsy (CP) is often described as a group of nonprogressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising at any time during early brain development.

The tone abnormalities of CP can range from spasticity[26] to hypotonicity,[27] can be mixed and can vary in one child during the day. An important component of the definition of CP is that it is nonprogressive. In fact, many children improve functionally over time consistent with the nature of pediatric neurologic maturation.

Central to the definition of CP is the concept that it is a disorder of the brain and not of the musculoskeletal system. Understanding that CP is a neurodevelopmental disability with its primary impact on the motor system will assist in understanding the impact of CP on a child's or adult's functional skills.

Cerebral palsy (CP) is a neurodevelopmental disability, and is manifested through diverse forms and associated degrees of functional limitation of movement and posture. CP is mostly congenital, i.e., the time of causation is prenatal (before birth) or perinatal (from the onset of labour, until 30 days after birth). In Africa, the prevalence of CP is generally linked to the occurrence of birth asphyxia[28] / neonatal encephalopathy,[29] kernicterus[30] and neonatal infections. CP can also be acquiredas a result of trauma, abuse or postnatal infection in the early years. Although the condition itself is not of a progressive nature, potential detrimental sequelae are linked to its neurological origin, over the long term.

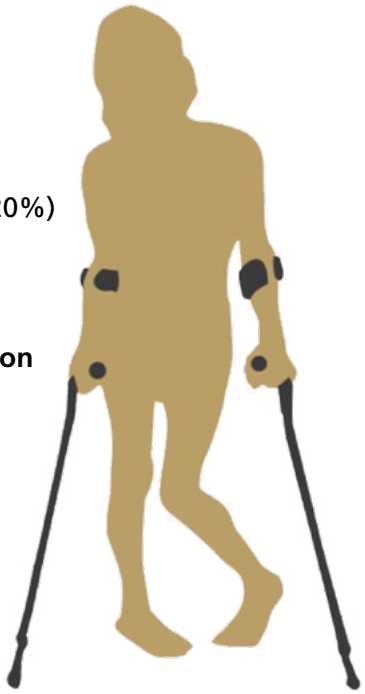
What is Cerebral palsy?

Cerebral palsy is a term often used in African contexts to describe all motor disability syndromes. Delegates reported that in many countries cerebral palsy is considered synonymous with birth asphyxia/ neonatal encephalopathy. Internationally accepted consensus definitions are relevant in resource-poor countries but the lack of diagnostic facilities makes excluding some of the 'non–cerebral palsy' conditions or mimics more difficult. Because of the perceived greater number of children with cerebral palsy secondary to postnatal complications in Africa (such as meningitis, cerebral malaria, traumatic brain injury), the 'ceiling' age at which one can call a postnatal insult 'cerebral palsy' may be more important in this group than in developed countries where postnatal etiology makes up a small proportion of reported cerebral palsy populations.

Some groups in Africa include children who acquired brain injury up to the age of 5 years. The group concluded that using the international consensus definition age of 2 years was the most useful way to achieve consistency on the reporting of the topic. There was also a robust discussion on whether certain acquired conditions should be included in the cerebral palsy group. The consensus was that congenital infections such as cytomegalovirus and rubella should be included, as well as traumatic brain injury and neurologic sequelae of meningitis (occurring at less than 2 years of age), providing they also met the other inclusion criteria for the diagnosis. Conditions that are included by some centers in Africa, such as neurologic impairment secondary to human immunodeficiency virus (HIV) encephalopathy, as well as disorders of muscle and peripheral nerves, should be excluded. The inclusion of these conditions in 'motor disability' rather than "cerebral palsy' clinics for service purposes was proposed.

Various classification systems exist. The essential characteristic of CP is neuromotor impairment. By means of the **Gross Motor Function Classification System (GMFCS)**, the measure of impairment severity is categorised in accordance with associated functional limitation. The GMFCS five level-classification, developed for different age groups[31] of children with CP, runs complimentary to the holistic approach taken by the ICF, inter alia, with a view to addressing the child's unique developmental needs. The emphasis on self-initiated movement, specifically sitting and walking and the need for assistive technology, is especially helpful in planning interventions. (Figure 3)

Cerebral palsy categories



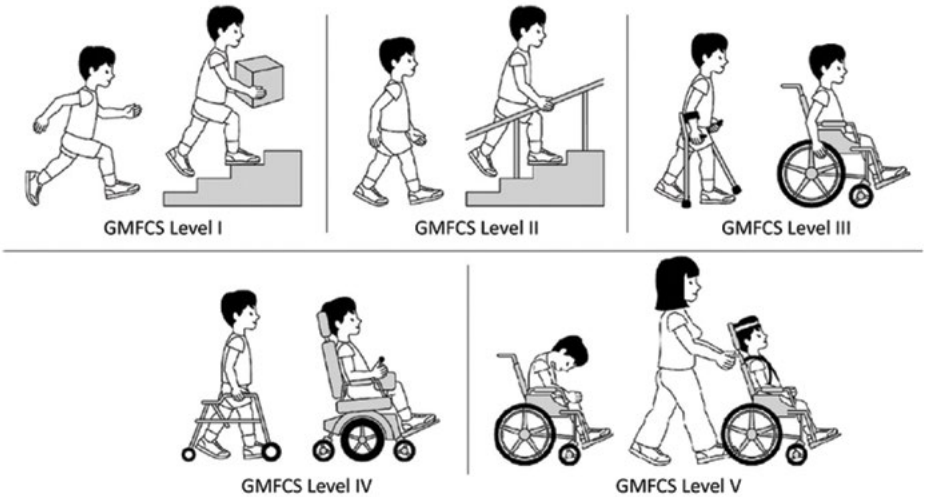
CP can be described in terms of four types of motor impairment:

- Spasticity, or muscle stiffness (70-80% of children with CP)
- Dyskinesia, or excessive irregular involuntary movement (10-20%)
- Ataxia, or disturbance of balance and body posture (5-10%)
- Combination of the above

CP can also be described according to a topographical classification that relates to the parts of the body that are affected:

- Monoplegia, or one limb (arm or leg)
- Hemiplegia, or one side of the body (face, arm and leg)
- Triplegia, or three limbs (both legs and one arm)
- Quadriplegia, or four limbs (both arms and both legs)
- Diplegia, or all four limbs, with legs more affected than arms
- Paraplegia, or both legs.

Figure 3: Gross Motor Function Classification System (GMFCS) levels



As motor development is compromised, it is not surprising that CP is also associated with oromotor dysfunction. Oromotor (oral-motor) development refers to the sequential maturation and practice of increasingly sophisticated movement and coordination skills that involve the lips, tongue, jaw, teeth, as well as the hard and soft palates. Oromotor function is required for feeding, swallowing and speech production. Disruption in developing these skills is related to drooling, gagging, aspiration of food (or saliva)[32] and choking, and delay in expressive language.

It can have long-term implications for sufficient oral motor practice if not addressed. A positive relationship between severe motor impairment (GMFCS Levels lV and V), degree of oromotor dysfunction and underweight nutritional status among children in the age group 2 to 18 years with CP has been identified. Chronic aspiration is linked to wheezing and bouts of pneumonia. Drooling frequently gives rise to issues related to social acceptance for the child and her/his family.

CP is also associated with gastrointestinal dysmotility[33] or a dysfunctional digestive system. As a result, eating difficulties, dysphagia,[34] gastrointestinal reflux,[35] delayed gastric emptying[36]and constipation[37] are prevalent.

Calorie intake in children with CP is lower compared to children of the same age. The analysis of the three-day menu demonstrated significantly lower energy intake in children with moderate and severe developmental disorders, that suggests there is a feeding problem as a cause of malnutrition of these children. The reason for that may be modified food texture, as well as food inappropriate for the patient's age. Some patients are dependent on their parents/carers' feeding due to their inability to express hunger and thirst and inadequate hand-mouth coordination.

The energy needs of children with CP are different, depending on the type of CP they have. Many children with CP have reduced energy requirements. Children who are physically active, those involved in intensive rehabilitation, children with seizures or frequent infections may have increased energy needs. (Melunovic et al 2017: 68)

Dysarthia is described as a motor speech disorder resulting from disturbed neuromuscular control or the speech mechanism itself.

Dysarthia occurs in different degrees and in correspondence with the type of CP. It is associated with delayed language development. Facilitation of communication is guided by its impact on the specific child.

1 Group 1
Speech is very severely compromised and AAC is required for all communication.

2 Group 2
Speech is somewhat less affected and the child is subsequently able to communicate around their basic needs. However, AAC support for communication is still required.

3 Group 3
Adequate functional speech for basic communication is available. AAC is only employed to aid learning of language.

4 Group 4
AAC is seen as a backup. The child's speech challenges are minor, and verbal communication is functional in all respects.

In an examination of the communication proficiency of 124 full term or preterm two-year-olds with CP, with motor functionality distributed over the five GMFCS levels, communication difficulties were found to be pervasive. The group of two-year-olds born full-term with motor dysfunction at GMFCS level V had very limited verbal communication. The researchers concluded that more care should be taken to not only screen for functional ability (ambulation) at an early age, but also for communication skills.

Cognisant of the developmental immaturity of young children as well as the potential impact of dysarthria on language production, optimal communication should be enhanced. The child should have visual cues available to support their verbal communication, and if necessary, the conversational partner should be prepared and trained for auditory reception. By looking at the child's mouth, the listener will grow familiar to the child's way of speaking. The noise levels of the environment chosen for verbal exchange should be conducive to communication. Further, motor symptoms associated with the type of CP of the child, are often intensified by experiencing emotion. Both anxiety and excitement can make tremors or involuntary movements more pronounced.

Despite a substantial link between CP and ID (and/or SLD, it cannot be assumed that every child with CP has a cognitive or learning disability as well.

4.6 Paediatric brain injury

According to international classification, acquired brain injury (ABI) is an injury to the brain after birth that results in partial or full-scale functional disability and/or psychosocial impairment., and the individual's functioning is negatively impacted to a marked degree. ABI has two categories: traumatic brain injury (TBI) and non-traumatic brain injury (non-TBI). (Figure 4)

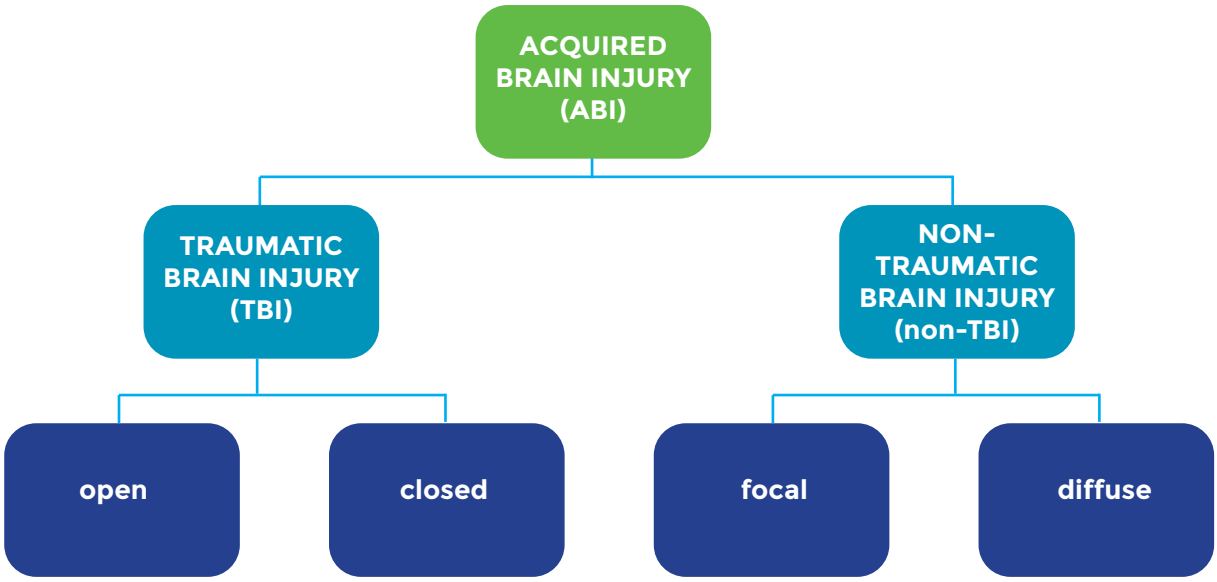
TBI refers to a traumatic insult to the brain, capable of producing brain damage and associated with functional impairment. These traumatic insults are usually caused by a physical blow or wound to the head that is sufficient to result in altered consciousness and may lead to neurological or neurobehavioural sequelae. (Anderson et al 2001: 129)

TBI is a general cause of acquired childhood disability, with the highest prevalence in the age groups younger than four years and late adolescence.

The most common causes of TBI are:

- **falling**
- **motor vehicle accidents**
- **sport-related accidents**
- **physical assaults.**

Figure 4: Classification of Acquired Brain Injury (ABI)



Open TBI is a confined injury resulting from penetration of the brain through the skull. Because the injury is confined to a specific area of the brain, it is clear which associated functions are affected and the outcome can be predicted.

Closed TBI is a brain injury following an impact to the head, for example in a motor vehicle accident. The effect of the injury is not predictable, because damage occurs not only at the point of impact, but also in other parts, owing to the movement of the brain inside the skull as a result of the blow to the head. For example, with a very hard knock against the forehead, a coup[38] injury is sustained on the frontal part of the brain. Simultaneously a countrecoup[39] injury is incurred at the back of the brain, with the brain having moved backwards against the protruding bones of the skull. Any secondary injuries to the brain will consequently also have a detrimental effect.

> A non-TBI is defined as an ABI resulting from non-traumatic factors such as malignancy, infections, degenerative processes or stroke.
> (Russo et al 2009: 98)

The neurological consequences of these injuries can either be specific or pervasive. As some conditions are associated with injury at a specific location in the brain, the damage is **focal** and its implications localised, e.g., cerebellar astrocytoma,[40] a major brain tumour which develops in children.

Hydrocephalus,[41] - an abnormal buildup of fluid in the ventricles (cavities) deep within the brain - is not considered a TBI, but causes **diffuse** damage with severe neurological consequences.

Early onset hydrocephalus occurs in children within the first year of life as a result of congenital or perinatal disorders. The increased cranial pressure in the brain can cause increased head size and lasting damage to the brain tissue as it gets compressed and squeezed against the skull. A common treatment for children with hydrocephalus is to surgically implant a shunt to drain the extra cerebral spinal fluid into the abdominal cavity. Children with early onset hydrocephalus have been found to have deficits in both fine and gross motor coordination, visual-motor and visual-spatial processes, some language delays, problem-solving skills, and focused attention. (Miller 2007: 73)

Table 4: Dysfunction associated with moderate to severe TBI

DYSFUNCTION		
Physical	**Cognitive**	**Cognitive**
• Altered vision and/or hearing • Spatial orientation difficulties • Reduced speed • Weakened balance • Diminished strength and endurance • Change in speech • Difficulty with eye-hand coordination • Different muscle tone	• Changed perception • Disturbed attention and concentration • Reduced information processing • Thinking and reasoning requiring effort • Diminished memory • Compromised decision-making and judgment • Impaired planning and organisation skills • Difficulties with speech, language and communication • Resistant to change • Oblivious to strengths and weaknesses	• Emotional outbursts • Physical aggression • Defiance • Lethargy • Reduced social skills • Impoverished adaptive functioning

Brain injury is classified in terms of severity: mild, moderate or severe. The impact of brain injury is frequently underestimated. Although a mild TBI may have no lasting consequences, continuing dysfunction runs parallel to moderate to severe TBI. (Table 4)

The relation between injury severity and cognitive deficiencies is clear. An insult to the developing brain can disrupt learning processes in various ways. To determine its neurological impact, the developmental course between sustaining the injury and the time of assessment should be considered. The age at which the injury happened is another factor to consider.

According to the Kennard principle, "the earlier in life brain damage is sustained, the better the recovery." In the young developing brain new neural pathways can form and even reorganise due to the high frequency of synaptogenesis[42] that is characteristic of this period. However, while the Kennard principle appears to explain the difference in recovery between children and adults when functions related to language were damaged, it does not hold true for all damage sustained, eg. the domains related to spatial cognition. The younger the child, the less existing or learnt information is available to draw upon when new information is learnt in the recovery period.

> (G)ross motor skills appear to be impaired after acute hospital care discharge, whereas fine motor coordination, visual perceptual deficits, and language deficits may become manifested when the child starts preschool. (Miller 2007: 66)

The first years immediately following the TBI, holds the most promise for rehabilitation while the brain heals. The sleeper effect is also an important factor when treating children with a TBI. The sleeper effect is cognitive dysfunction which only becomes evident at a later point in time as a consequence of the injury. The possible sequelae of contracting meningitis is an example.

The fact remains that every child is unique. Each child with an ABI has an individual developmental profile of strengths and weaknesses that emerge in interaction with various contextual factors.

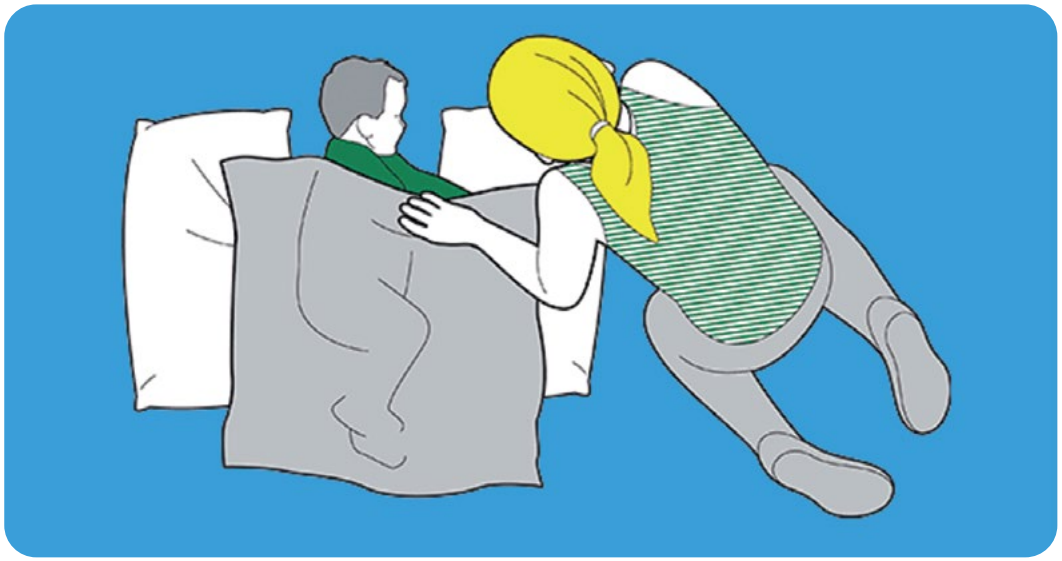
4.7 Epilepsy

Epilepsy is a disorder in which nerve cell activity in the brain is disturbed, causing seizures. Recurrent abnormal electrical discharges in the brain affect one or more or the following brain functions: motor, sensory, cognitive, speech, behavioral, emotional, and psychological.

During an epileptic seizure there is usually abnormal, excessive or synchronous neuronal activity in the brain. Inaccurate identification of seizures can preclude effective treatment.

Epilepsy is the most common neurological condition in childhood. Its incidence is highest during infancy and declines as children mature. Epilepsy is a symptom (rather than the cause) of central nervous system (CNS) dysfunction. CNS dysfunction is either biological or acquired. It is estimated that 67% of active epilepsy among children in Africa is closely associated with genetic, metabolic and brain structure causes. Moreover, in comparison to children in other parts of the world, the link with the prevalence of ABI is more pronounced. There is a significant treatment gap for active epilepsy between urban and rural areas. (Table 5)

> (I)n most of the Northern states of Nigeria, there has been a very limited uptake of immunization, leaving children unprotected against illnesses that might cause intellectual impairment. Primary health care clinics have to deal with clients who practice both the Western and traditional ways of healing. Children with very high fevers may be treated with traditional methods which are sometimes successful but, when unsuccessful, may lead to complications that could then result in permanent disability. (McKenzie & Ohajunwa 2017: 96)



Epilepsy and the developing brain*

According to Anderson et al (2001: 279-280), "(t)here appear to be important differences in the response of the immature brain to a seizure disorder, in comparison to the adult brain." The developing brain has many characteristics that result in it being more epileptogenic than the adult brain – characteristics that are becoming better understood through studies of animal models of epilepsy. These models suggests that in the young, seizures have different focal neurophysiological substrates and patterns of propagation and spread, as well as different mechanisms of seizure control. As a result the behavioural manifestations of seizures and responses to treatment (i.e., anti-epilepsy medication) may be age specific.

The immature nervous system also appears to differ from the mature CNS in terms of the impact of seizures. There is evidence from animal studies that the immature CNS is relatively invulnerable to the impact of seizures; however, evidence is also emerging from laboratory studies suggesting that epileptic activity may have a profound influence on developing neurons. As Moshé et al. (1996)* point out, consideration of these age-dependent effects is essential if the impact of epilepsy in childhood is to be fully understood.

*Moshé, S.L., Koszer, S., Wolf, S.M. & Cornblath, M. 1996. Developmental aspects of epileptogenesis. In Wyllie, E. (Ed.) The treatment of epilepsy: Principles and practice. Second Edition. Baltimore: Williams & Wilkins.

In understanding epilepsy and its management in early childhood, the developmental factors need to be taken into consideration.

- **Febrile seizures** are prevalent in children aged three months to five years, It is associated with fever not caused by brain infection. Although quite common at an early age, febrile seizures usually do not develop into other forms of epilepsy at a later stage. Research suggests a genetic basis for this type of seizure.

- During infancy, seizures – and particularly seizures that are difficult to control – can be an indication of a neurodevelopmental dysfunction, and further investigation should be considered.

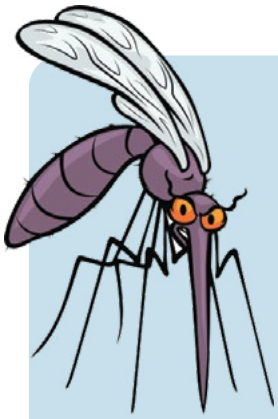
- **Epileptic encephalopathies** are serious brain conditions that manifest at an early age. There are different types of seizures and treatment may not be simple. An electroencephalogram (EEG) is used to test the electrical activity of the brain and detect any abnormalities.

West syndrome is usually detected in children aged between three and eight months. West syndrome may develop into Lennox-Gastaut syndrome with the onset usually between one year and seven years of age. Epileptic encephalopathies have to be monitored for developmental regression, because they can have a damaging effect on neurological and cognitive development.

- **Acquired epileptic aphasia** has its onset during the preschool years. Seizures occur in both hemispheres of the brain, in the central temporal and parietal regions. A lapse in development of expressive and receptive language is associated with this form of epilepsy, ie., word deafness[43] and auditory agnosia.[44] It is linked with cognitive and behavioural challenges as well.

- **Absence seizures** usually occur among children of school-going age, from five years upwards. These seizures are characterised by brief episodes of altered consciousness in which the child suddenly stops activity and stares vacantly for a short time, and then continues the activity, with no evidence of confusion resulting from the seizure. This kind of disrupted attention in the learning environment has a negative impact on the processing of information.

- **Pharmacological intervention** by means of anti-epileptic drug (AED) treatment has to be closely monitored in children younger than five years of age. During early childhood AEDs are metabolised faster than in middle childhood.



According to Wilmshurst et al (2014: 36-37), the prevalence of epilepsy in Africa is underestimated.

The proportion of focal epilepsies appears to be higher in children living in Africa than elsewhere. The incidence of perinatal insults; infections of the CNS, such as bacterial and tuberculous meningitis; and head trauma in children is greater in Africa than elsewhere. In addition, Africa has the highest burden of parasitic infections, such as *falciparum malaria* and *onchocerciasis*, both of which are associated with the development of epilepsy. In addition, parasitic infestations such as the *Toxocara* species and *Toxoplasmosis gondii* are ubiquitous in Africa, and infections with these organisms are associated with epilepsy. Neurocysticercosis is common is some parts of Africa. Parasitic infections are believed to cause up to 27% of pediatric epilepsy in some areas, with antenatal and perinatal risk factors of more effect in other regions. Human immunodeficiency virus infection is prevalent across Africa, especially sub-Saharan Africa, where 90% of infected children reside. Most seizures associated with human immunodeficiency virus infection appear to be caused by opportunistic infectious organisms, although it is associated with epilepsy per se.

Table 5: Causes of epilepsy among children in Africa

CAUSE	PERCENTAGE
Genetic, metabolic and brain structure conditions	67
CNS infections	13
Perinatal insult	11
Head trauma	08
Other	01
TOTAL	100%

Seizures present in various ways and are organised according to systems of classification. The basic classification of epileptic seizures according to the International League Against Epilepsy (ILAE) is made on three levels: onset, awareness and symptoms.

Onset refers to the seizure's origin in the brain.

Focal onset: This refers to the start of a seizure in a neuronal network in either the left or the right hemisphere of the brain.

Generalised onset: Generalized onset means that the seizures start in networks of neurons that run in the two hemispheres of the brain, and therefore "bilateral" networks.

Unknown onset: Unknown onset is used as a "placeholder", because the site origin of the seizure is not yet known. (see Figure 5)

The next level of classification concerns awareness, defined as 'knowledge of self and environment.'

Awareness during a focal seizure can either be full or impaired.

The third level describes symptoms: motor or non-motor.

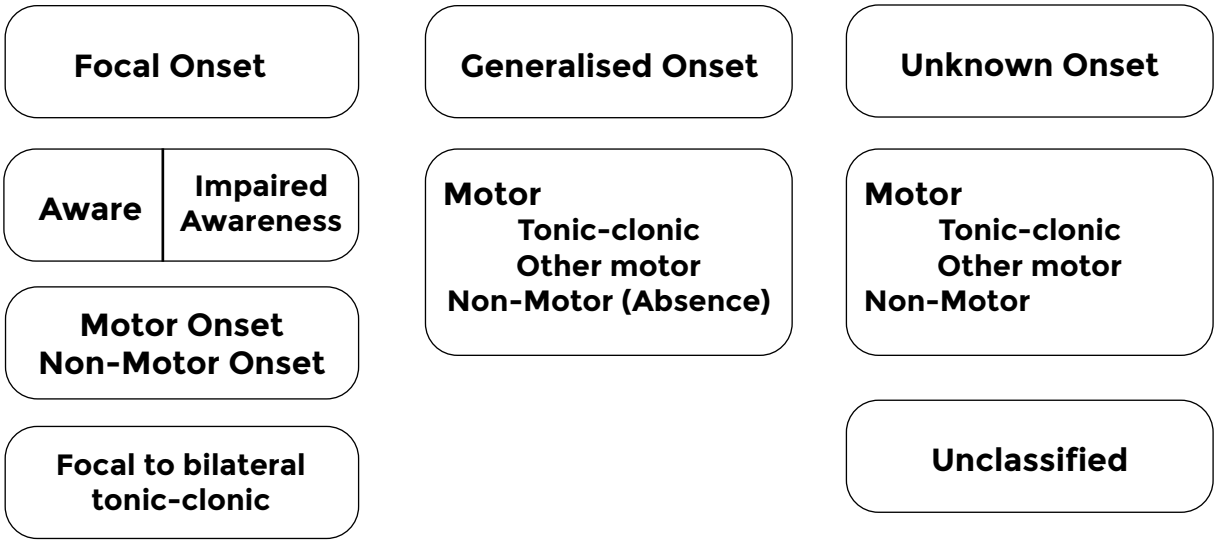
Motor onset is related to muscle activity in the trunk of the body and/or the limbs during seizure.

Non-motor onset includes sensory, emotional and/or behavioural symptoms. The 'focal to bilateral tonic-clonic' type of seizure is common and derives its name from the pattern of activity ie., spreading and involving more networks.[45]

Generalized onset seizures are mostly characterised by impaired awareness. The distinction is made between motor and non-motor activity. Absence seizures are non-motor.

Seizures that are classified as **'unknown onset'** can present either with motor or non-motor symptoms. The subcategory **'Unclassified'** is reserved for seizure patterns that do not fit the other classification categories and also seizures for which insufficient information is available to categorise.

Figure 5: ILAE (2017) Basic seizure type classification



> This could be the result of neuronal damage resulting from frequent seizures or seizures in an immature brain, the effects of AEDs, or an underlying pathology, or genetic defect, contributing to etiology for both seizures and cognitive/attention deficits. (Williams et al 2016: 287)

Therapeutic intervention aims at seizure control, no side effects and optimal quality of life. It is not always possible to effectively control seizures by means of AEDs. Goals are subsequently adjusted to fewest seizures, fewest adverse events and best quality of life.

Epilepsy is a health condition that has a marked association with ID and ASD respectively. Also, a positive correlation exists between the severity of ID and epilepsy: It is less likely that children with ID in the mild to moderate range will have epilepsy, and alternatively, more likely that epilepsy will occur among children in the severe to profound group. There is also a strong association between paediatric epilepsy and ADHD. Onset at an early age is associated with slower motor speed, and cognitive dysfunction that includes attentional challenges. Memory impairment is also related to epilepsy.

4.8 Foetal Alcohol Spectrum (FASD)[46]

Foetal alcohol spectrum (FASD) is a preventable developmental disability caused by the foetus's exposure to alcohol through the mother, during the prenatal period.

The first trimester and the last two months of gestation are the most vulnerable periods for neurological damage, although consistent alcohol consumption by the mother, throughout the entire pregnancy, has the worst effect. The foetal brain incurs structural changes to and the developing CNS is damaged. The following distinctions can be made in the case of FAS:

- heavy alcohol use or binge drinking: FAS (Foetal alcohol syndrome); and
- lower alcohol use with milder symptomology: partial FAS, FAE (Foetal alcohol effects), ARND (Alcohol related neurodevelopmental disorder) and ARBD (Alcohol related birth defects).

The facial features associated with FASD are distinct. FASD is also associated with a curved little finger and a 'hockey stick' crease on the hand palm between the second and the third finger. There is also a delay in the child's growth. (Figure 6)

FASD is synonymous with compromised neurodevelopmental challenges, including:

visual and hearing impairment,

motor incoordination,

limited visual-spatial skills,

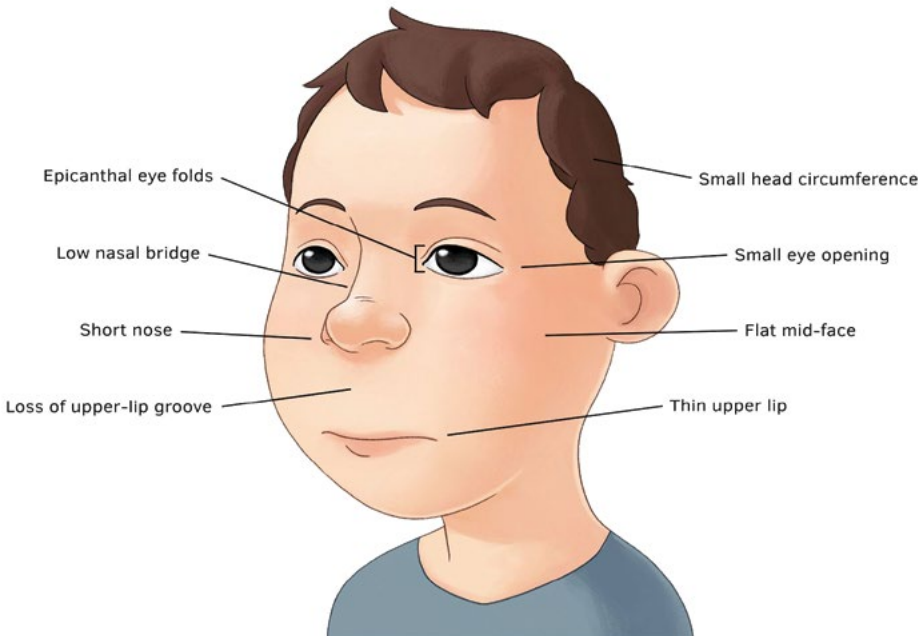
scholastic challenges,

overstimulated, and

aggressive behaviour.

Without necessarily obtaining psychometric test scores that reflect ID, **the relationship between FASD and neurocognitive impairment is clear.**

Figure 6: Essential and associated facial features of FAS



The acronym ALARM is an apt descriptor for neurocognitive impairments related to FAS:

Adaptive functioning

Adaptive behaviour means the child is on par with their peers regarding self-sufficiency and social functioning. Children with FAS often appear more 'adjusted' than they really are.

Language

Due to 'superficial talkativeness' the verbal abilities of persons with FAS are overestimated. Both expressive and receptive language abilities pose difficulty during communication and complex language is difficult to understand due to limited comprehension of syntax (language structure) and semantics (meaning of words).

Attentional difficulties

FAS is associated with ADHD. Inattention, impulsivity and hyperactivity are therefore factors to take into consideration. Children on the foetal alcohol spectrum can be overactive and disruptive. They may get stuck on a stimulus, have difficulty registering information, not use all available sources of information during problem solving and find it hard to exercise impulse control.

Reasoning

Children with FASD display a specific impairment in basic numerical processing abilities, such as the ability to mentally represent and manipulate numbers and quantities.

Memory

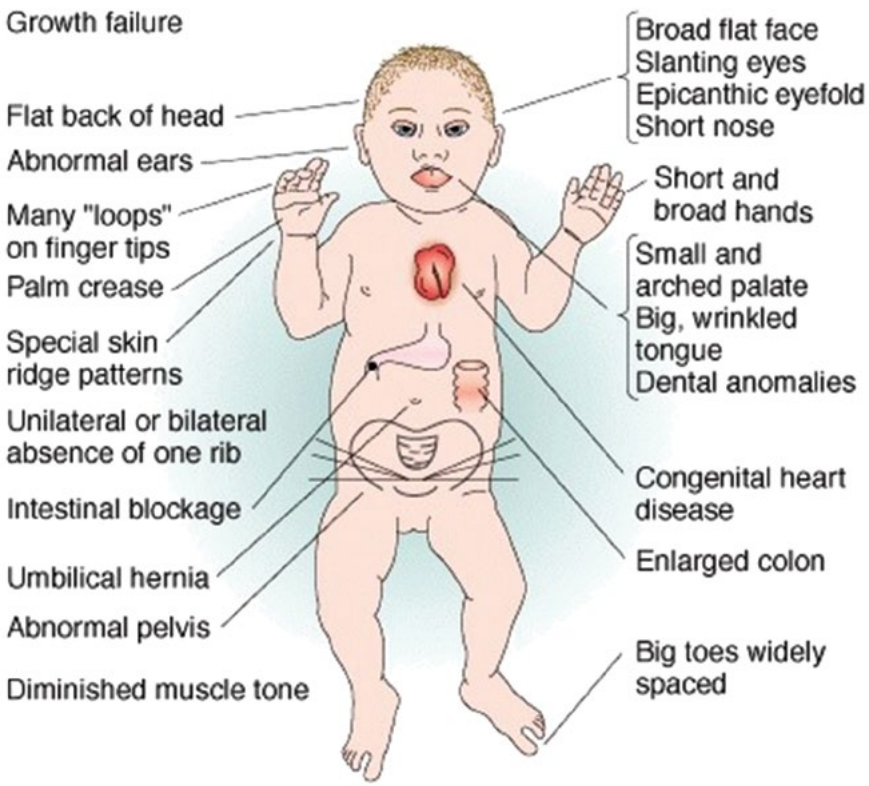
Encoding of learning material is difficult, but equally well retained in comparison to children who do not have developmental challenges. However, during recall, confabulation often occurs - filling memory gaps with distorted or fabricated information in recollection.

Neuropsychological testing is recommended as part of the comprehensive developmental assessment conducted by a multidisciplinary team.

4.9 Down Syndrome (DS)

Down syndrome (DS) is a general genetic condition resulting from chromosomal deviation. It is distinguished by specific physical characteristics. These features are unremarkable at times, or varied in degree. (Figure 7)

Figure 7: The physiological characteristics of Down syndrome



Most children with DS develop speech although some children remain unintelligible. Despite delayed speech learning, vocabulary is often a relative strength. While communicating however, this advantage remains limited due to the challenges of managing the structure of language.[47] Impairment of short-term memory is linked to phonological (speech production) impairment, eg. speech sound disorder.

Speech sound disorder

Speech sound disorder is one of the developmental disabilities of communication.

Speech sound production describes the clear articulation of the phonemes (i.e., individual sounds) that in combination make up spoken words.

Speech sound production requires both the phonological knowledge of speech sounds and the ability to coordinate the movements of the articulators (i.e., the jaw, tongue, and lips,) with breathing and vocalizing for speech. Children with speech production difficulties may experience difficulty with phonological knowledge of speech sounds or the ability to coordinate movements for speech in varying degrees. Speech sound disorder is thus heterogeneous in its underlying mechanisms and includes phonological disorder and articulation disorder.[48]

A speech sound disorder is diagnosed when speech sound production is not what would be expected based on the child's age and developmental stage and when the deficits are not the result of a physical, structural, neurological, or hearing impairment. Among typically developing children at age 4 years, overall speech should be intelligible, whereas at age 2 years, only 50% may be understandable. (APA 2013b: 44)

Children with DS display a relatively strong ability for visual spatial processing. Providing complementary graphic information to spoken language supports communication. Neurodevelopmental tasks that require elements to be organised in a specific order – known as successive processing - can be challenging, eg. writing and the understanding of complex verbal information.[49]

Research on services for children under-5 shows that measures of cognitive capabilities increase between one-half and three-quarter standard deviations, which are highly significant. When children with Down Syndrome do access services, the typical deterioration in cognitive capacity that occurs between the ages of 12 and 18 months can be prevented almost entirely. Unlike many other causes of mental disability, Down Syndrome can be quite easily detected. (Mont 2019)

Intellectual impairment is clearly noticeable in children with DS. Adaptive functioning usually reaches a plateau during middle childhood, and may show a steady decline thereafter, particularly in the social domain.

Research on behavioural phenotypes[50] of DS has revealed the following relative strengths and weaknesses:

- Receptive, rather than expressive, language, is a strength.
- The child's receptive vocabulary compensates for impaired verbal short-term memory (recollecting what was recently said).
- Visual short-term memory (recollecting what was recently seen) is stronger than verbal short-term memory.
- Episodic memory (retaining details of a personal experience in memory) is a weakness.

4.10 Visual disabilities

The senses of sight and hearing are involuntary – they do not require will power to be employed in making sense of the environment.

> Vision is active as long as the eyes are open and hearing functions continually unless its organ is obstructed.
> (Kaufman & Hallahan 1988: 318)

Vision is the primary sense utilised by humans during daily functioning. Consequently, visual perception develops sooner than auditory perception. Any infant with low vision or who is blind, and who does not receive appropriate support from caregivers from the time of birth, will likely be developmentally compromised. For example, the early motor development of babies with visual impairment is delayed, because it is not (sufficiently) prompted by visual stimulation.

There are also other clear differences in motor development in comparison to babies with eyesight – developing motor control of the body parts is delayed and while they have to rely on auditory perception (as opposed to visual perception), their sense for laterality and directionality develops later. Limited or absent visual perception also has an impact on developing gross and fine motor coordination.

The following factors are relevant in terms of the developmental pace during early childhood:

- type of eye condition,
- age of onset,
- degree of residual vision and
- measure of support.

For pre-schoolers the implications of minimal participation in play and/or 'impoverished' activities of play as a result of visual limitations are pervasive - the perceptual, cognitive, language and social developmental domains are affected.

In order to achieve optimal development, young children with visual disabilities require the following assistance and support:

- Babies are encouraged to move by capitalising on the other senses, for example, constantly talking to them as a way to prompt activity for physical closeness.
- Motor development is consciously facilitated, for example by bouncing them up and down and allowing activities for climbing up and down.
- For spatial development, infants are assisted to use their own bodies as the point of reference for mastery of laterality and directionality.
- All the other senses are actively stimulated and their use practised.
- Young children are discouraged from putting everything in their mouths.
- Auditory memory is developed and strengthened.
- They practise using their tactile (touch) and kinaesthetic (movement) senses to explore and orient themselves in their surroundings.
- The expansion of vocabulary is scaffolded by concrete multi-sensory experiences.
- Verbal messages are constructed to clearly convey cause-effect relationships, if applicable.
- General description in terms of colour is still used.
- Where applicable, their external environment is interpreted to them which helps to make sense of events.
- Teaching activities of daily living (ADL) promotes age-appropriate independence.
- Facilitating ample opportunity for interaction with their peers.
- Young children are given the opportunity to use their own ideas.

Children who are born blind, are clearly disadvantaged in terms of their perceptual development and have to rely on their sense of hearing for cognitive development.

For the sighted child, the world meets him halfway. What he sees encourages him to move further out into his environment and to explore it. He learns literally hundreds of thousands of things from observation, imitation, and identification, without any effort on his part or on the part of his parents or teachers. The visually impaired child is dependent on others to organize, explain, and interpret the strange and confusing world around him. (Scott in Hallahan & Kaufman 1988: 318-319)

Sharpened auditory perception compensates for diminished visyual input. Visual impairment does not significantly affect language development. Developmental progression is expected to be slower than expected. Absent or limited visual ability slows down perception to various degrees, resulting in reduced quality of conceptualisation. In general, children with low or no vision function cognitively on a par with their peers who do not have any impairment.

In comparison with their peers however, they lack the ability to integrate visual information with other sensory information. Abstract conceptualisation can be very challenging and tasks are therefore rather approached concretely – by means of their sense of touch. Object perception by way of touch is a successive process, and not a simultaneous process[51] as for children with typical vision.

Children with low vision or who are blind utilise two kinds of touch for haptic (touch) perception:

Synthetic touch

the exploration of objects small enough to be enclosed by one or both hands.

Analytic touch

the touching of various parts of an object and mentally constructing these separate parts.

Comprehension of spatial concepts is a major challenge, especially when tactile perception and kinaesthesia cannot be combined for conceptualisation. Initial concept development concerning numbers and time may also be challenging for the visually impaired child.

Various conditions can cause low vision or blindness. Some conditions relate to the eyes as sensory organs, and other conditions have neurodevelopmental links. Examples of **eye diseases** that can cause marked visual challenges during the developmental years are glaucoma and cataracts. Glaucoma is caused by increased pressure within the eyeball, and cataracts cloud the lens causing blurred vision. Retinal detachment leads to 'blind spots' in the field of vision due to specific areas of the retina failing to register light stimuli. When the retina receives inadequate blood supply due to diabetes, retinopathy is the result. Eye muscle dysfunction is associated with conditions such as nystagmus[52] or strabismus.[53]

Congenital factors can be linked to visual disabilities. Infectious diseases (eg. rubella) contracted by the expecting mother can negatively affect the developing foetus. Premature birth and/or birth trauma can also have neurological complications leading to low or loss of vision. There is a marked association between albinism and visual disabilities. Impairment of vision may also be related to brain trauma due to damage to the occipital lobes and/or visual pathways in the brain.

Various visual examinations are performed in early childhood:

- ocular,
- external and pupil examination,
- red reflex testing, and
- ocular alignment and motility assessment.

Visual acuity is more easily tested when a child is at school-going age using the Snellen chart. More recently, the Sloan letters have been introduced. For children who cannot read the Snellen chart, the E-chart is used.

The measure of visual disability is determined by means of an ophthalmologic assessment of visual acuity and field of vision, and classified as either low vision or legal blindness. Some persons who are legally blind may still have limited functional vision. It is important to monitor children with low vision: some conditions are characterised by progressive deterioration. For example, with retinitis pigmentosa that starts at approximately six years of age, peripheral vision is gradually lost until the age of 15 years. Specific adaptations to the learning environment promote optimal functioning of children with visual disabilities, including the learning of the Braille system for communication.

The development of touch and kinaesthesis is also of the utmost importance for Braille reading and writing. Learners who are blind read Braille with their fingertips. They need fine tactile discrimination and fine motor coordination to move their fingers in a straight line over the Braille dots and to interpret the different combinations of dots as different letters and/or words. (Landsberg 2011: 375)

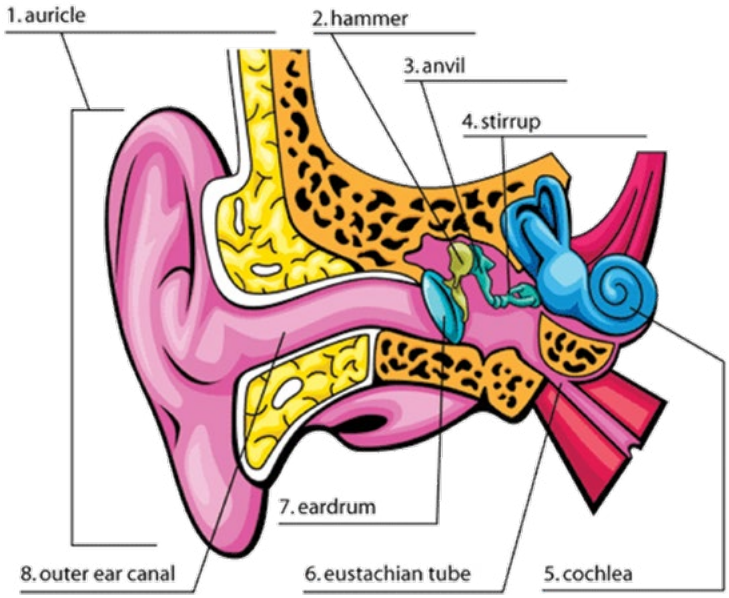
4.11 Hearing disabilities

Children with hearing loss form a diverse group of individuals.

Before a mother leaves hospital after delivery, her newborn's hearing is supposed to be screened by means of oto-acoustic emissions (OAEs). This is followed by the auditory brainstem response (ABR) test which is more reliable than the OAEs. At the infant's six weeks check-up, a third behavioural screening is conducted, which is largely subjective and may not be reliable. Pure-tone audiometric tests are used to test older children's hearing objectively. The degree of hearing disability is classified as either total hearing loss or is qualified as being in the range from slight to profound.

Intervention is dependent on the type of hearing loss.

Conductive hearing loss is the degree to which sound waves are conducted in either the outer or the middle ear. It may be caused by blockages in the outer or middle ear, and/or infections such as otitis media. The volume of sounds is affected and options for intervention include surgery, medication or amplification.



Sensorineural hearing loss is the inability of the inner ear to convert sound vibrations into electrical signals or of the auditory nerve that transmits these signals to the temporal lobe of the brain. Children who have total sensorineural hearing loss are suitable candidates for cochlear implants.

Central hearing loss or auditory processing dysfunction means that sound reaches the auditory nerve, but its transmission up until it reaches the brain, is not typical. This kind of hearing loss is associated with brain trauma or central auditory nervous system damage. Children with hearing difficulties utilise a range of hearing aids which are developed according to specialised acoustic technology.

Hearing loss can be either biological or acquired. Children may either be born deaf or develop hearing loss at a later stage. The assessment of hearing loss in relation to language development is vital and also determines the approach to intervention.

Prelingual hearing loss occurs before the age of two years when language has not yet developed, and may be caused by:

- maternal illness, eg. rubella (German measles) during the first trimester of pregnancy or herpes during pregnancy or thereafter;
- genetic deafness (hereditary);
- complications during birth and/or premature birth; and
- a severe spell of jaundice in the newborn.
- postlingual hearing loss occurs after the age of two years. Possible causes are:
- viral or bacterial meningitis which is an infection of the CNS;
- untreated otitis media / middle ear infection that turned into a chronic condition; and
- ototoxic medication, ie. medication prescribed for the treatment of bacterial infections, but which is noxious to the cochlea or vestibular structures of the ear.

Children with postlingual hearing disabilities have a language base that they can build on which benefits their future learning and communication development. The complete lack of exposure to language for children with prelingual hearing loss makes it imperative that they are taught Sign Language as a means of communication.

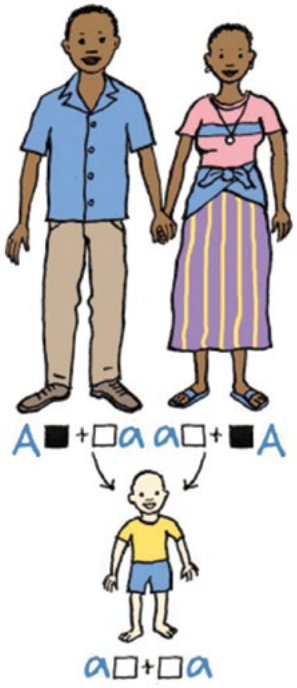
Hearing loss is associated with various speech and language difficulties during development. The window period for optimal language development in children with hearing loss is between the ages of one and four years. Early detection is thus required for best intervention. The earlier the loss of hearing, the greater its impact on language development. Children with hearing impairment cannot take advantage of the incidental learning of language within the social context as children with typical hearing do. Despite finding language acquisition very challenging, research shows that most children with hearing loss have average nonverbal intellectual functioning.[54]

Hearing aids are used for sound amplification for all kinds of hearing loss and can be fitted very soon after birth. Early intervention through stimulation of the auditory nerve, and thereby facilitating access to the world of sound and verbal communication, provides an opportunity for the child to benefit from learning experiences.

Cochlear implants may be considered for those children who do not meaningfully benefit from amplification. The cochlear implant converts sound waves into electrical impulses. In this way, the apparatus of the ear is bypassed and the auditory nerve is directly stimulated. A cochlear implant[55] improves the sensory registration of high frequency sounds and soft sounds. It cannot however, be regarded as a general procedure to turn complete hearing loss into the ability to hear.

A child's adaptive functioning is challenged by hearing difficulties. Unless an effort is made to include and involve children with hearing loss in daily life, they are unable to integrate experiences and the accompanying procedures and routines into their knowledge base. Isolating children with hearing impairment affects their concept development. Language limitations also impair emotional development. Without sufficient affective vocabulary, children are not able to understand their own emotional worlds, and related communication. Developing ToM is also delayed in these cases.

4.12 Albinism



From a human rights perspective, albinism can be regarded as a disability of childhood in various parts of Africa. The interaction between this health condition and its contextual aspects, determines the extent of the disability. According to 2011 demographic data, **Namibia has the highest prevalence of albinism in Africa: 1 in 1755 persons.** Considering that albinism is a skin pigmentation disorder, the harsh climate of Africa can be deemed a contributing environmental factor. Moreover, myths and/or superstition regarding children with a pale complexion in African communities creates barriers to safe and secure development. Some believe that children with albinism have 'incomplete' skin ie. skin missing its outer layer.

According to Namibian superstition, children with albinism are either a blessing or a curse. Others believe that the body parts of children with albinism hold good fortune and so they are made vulnerable and at risk for exploitation and abuse.

Albinism is a genetic condition. The most common type is **oculocutaneous albinism.** Two specific genes are associated with the lack of melanin pigment in the eyes, skin and hair. Among populations in Africa this condition is specifically linked to mutation of the OCA2 gene. Babies with albinism usually have typically pigmented parents.

Albinism in Africa

According to Brilliant (2015: 223)..."[a]ll forms of albinism are associated with problems of the visual system resulting in abnormalities of the retina, nystagmus, strabismus, foveal hypoplasia, abnormal crossing of the optic fibers, photophobia and reduced visual acuity. Oculocutaneous albinism (OCA) is a subgroup of recessive forms of albinism and characterized by a significant reduction or absence of melanin pigment in the eyes, skin and hair. Several genes are associated with OCA, although the most common forms are OCA1 and OCA2. OCA1 is caused by a reduction or complete lack of activity of the tyrosinase enzyme encoded by the TYR gene.

OCA2 is caused by a reduction or complete lack of activity of the P protein - a chloride channel that helps regulate the pH of the melanosome organelle where tyrosinase is active. Although OCA2 is found in all populations, certain populations have a relatively high incidence. The worldwide incidence of OCA2 is 1 in 36 000, but it is especially common among individuals of African descent. The phenotype of sandy colored hair, chalky white skin and blue or hazel eyes is very distinctive in African populations."

Persons with oculocutaneous albinism (or albinism) have **visual impairment** in varying degrees and e**xtremely sun-sensitive skin.** Visual impairment is non-progressive and includes nystagmus, strabismus, photophobia,[56] poor depth perception, refractive errors[57] and poor visual acuity. Even with optical correction, children still have low vision.

Extended exposureto the harmful effects of the sun (UVB), is a risk for the development of skin lesion cancers. In children with albinism, chronic skin damage may already be present at the age of 12 months.

Children with albinism in Africa have specific developmental needs for harm reduction, which includes:

- wide brimmed hats, sunglasses and long-sleeved clothing,
- sufficient supply of sunscreen preparations with SPF15 or higher,
- access to dermatological support for blistering, dry and chapped lips, sunburn and/or skin lesions,
- access to eye care and if applicable, visual support,
- social acceptance among peers and in the wider community.

5 NUTRITION AND NEURODEVELOPMENT

Taking a life cycle approach to development, there is continuous interaction between nutrition and neurological development. During **pregnancy**, maternal health and nutrition is key to the foetus's optimal development. Restricted growth results in low birth weight. If a woman is **underweight** during pregnancy, the infant is at increased risk for delayed brain development. The hippocampus (memory), the cortex, and auditory development are particularly vulnerable to malnutrition in early pregnancy. (Figure 8)

The interaction between neurodisability and macronutrient[58] malnutrition is apparent in the following circumstances:

Decreased food intake

Due to oromotor dysfunction, feeding can hold major challenges for children with CP e.g., difficulty with chewing and swallowing. Moreover, children who are nonverbal and/or who have limited or no locomotor abilities cannot compete with their siblings for food. When limited food is available in families, feeding of stronger and more active siblings may be prioritised.

Increased nutrient loss

Due to gastrointestinal dysmotility, children with CP do not always keep food down.

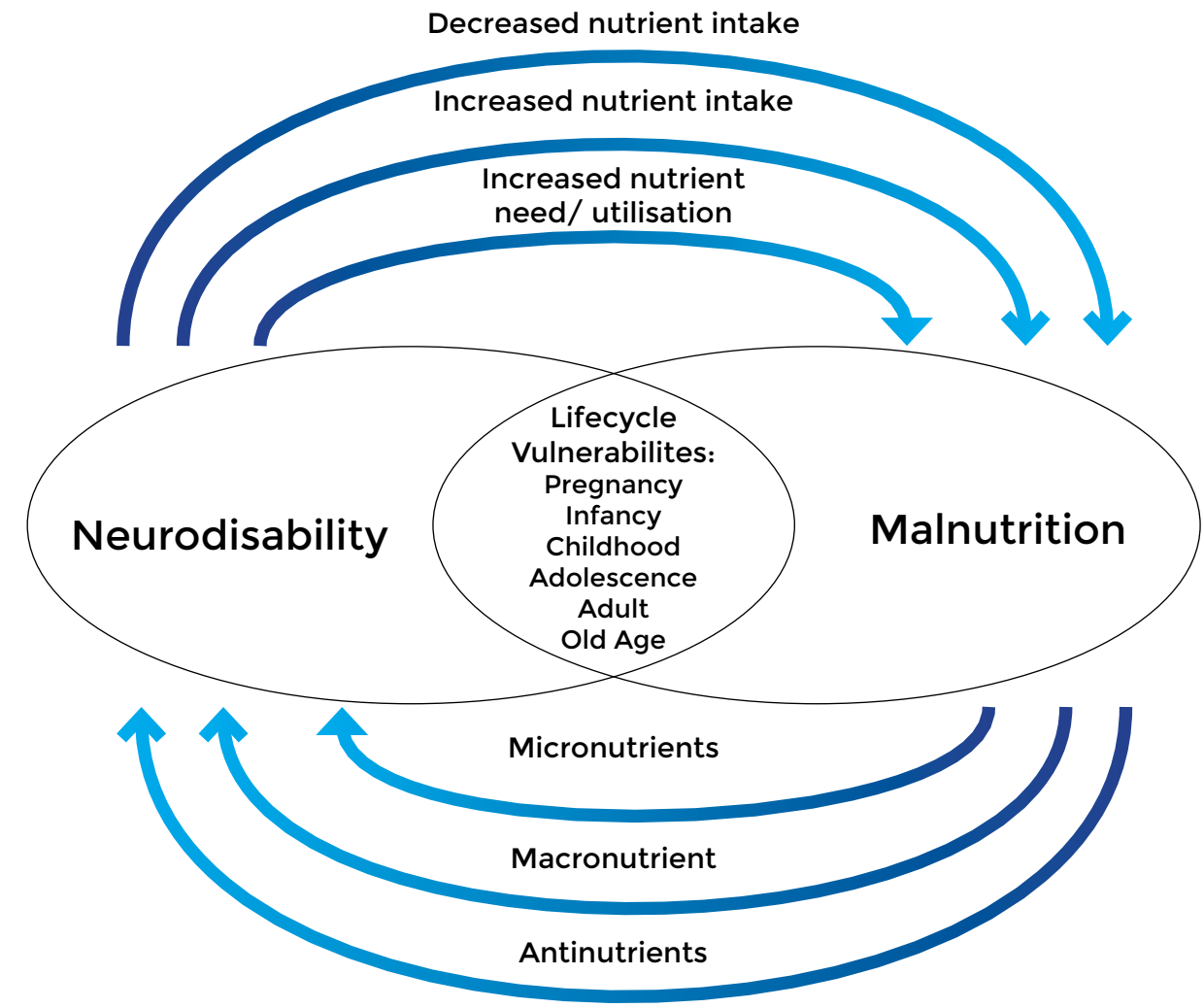
Increased nutrient requirement

While malnourished children stand a greater risk for infection, increased nutrients are required to combat infections.

Micronutrients are small amounts of vitamins and minerals that are required by the body, to enable chemical reactions. Micronutrient malnutrition affects neurodisability. A deficiency of vitamin B9 (folic acid) during pregnancy increases the risk of defective neural tubes. Night blindness can be caused by a Vitamin A deficiency. Deficiencies in iodine and iron are both related to compromised cognitive development.

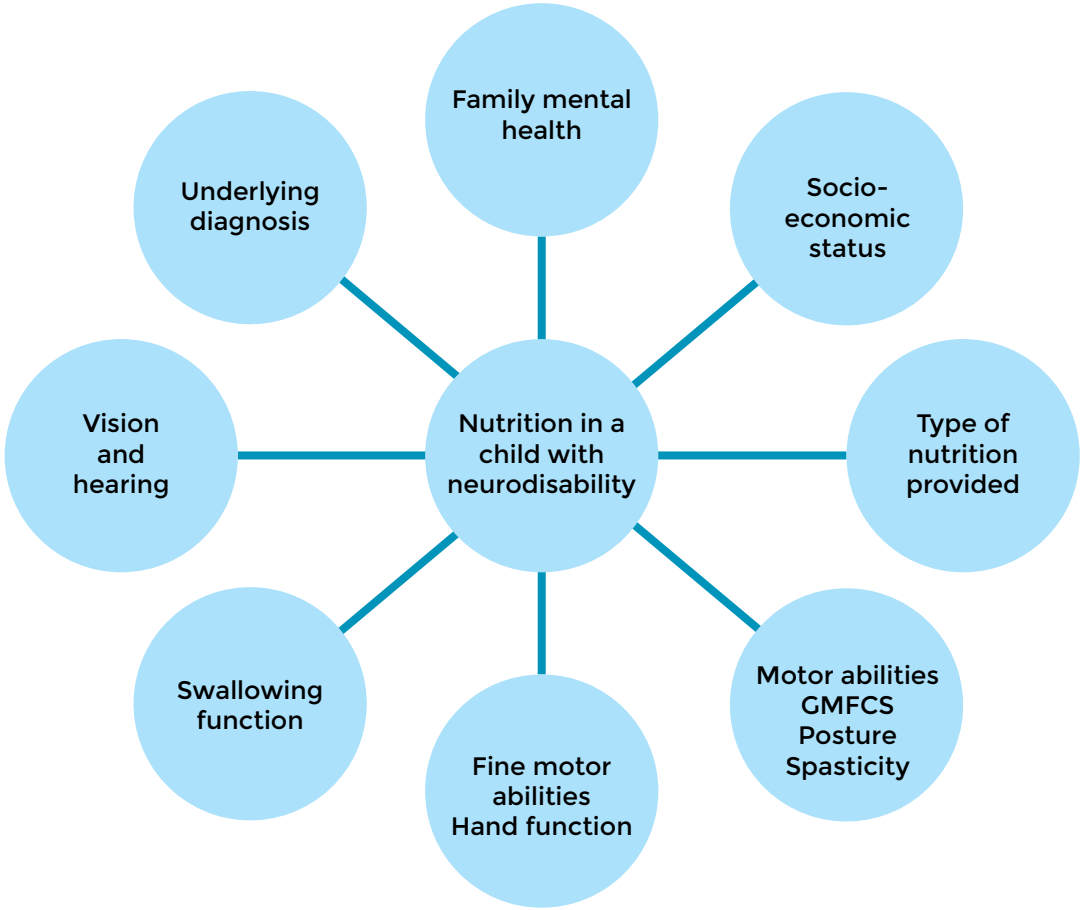
Antinutrients are naturally occurring substances found in foods made from plants that interfere with the uptake of nutrients and therefore nourishment. If the cassava root is prepared incorrectly, it can be toxic. It is associated with 'konzo', a disease that indicates motor neuron damage. Infections related to HIV, malaria and tuberculosis (TB) are associated with weakened immunity, malnutrition and a risk of neurological complications.

Figure 8: Interaction between neurodevelopment and nutrition



In Namibia, approximately one in four children under the age of five years is stunted. According to the Demographic and Health Survey 2013, 28% of children in the rural areas of Namibia were stunted in comparison to 17% of children in urban areas. The highest prevalence of stunted children were found in the Ohangwena region, and the lowest in the Khomas region (37% and 13% respectively).

Figure 9: Factors applicable to neurodevelopment – nutrition interaction



Due to the significant interaction between neurodevelopment and nutrition, both aspects should be included in neurodisability assessments. A comprehensive assessment should comprise of a physical and a neurological examination respectively, a developmental assessment as well as specific evaluations of language, cognitive and socio-emotional functioning. Concerning neurodisability and malnutrition, essential factors have to be monitored. (Table 6)

Table 6: Basic assessment of nutrition and neurodevelopment

NUTRITION	NEURODEVELOPMENT
Middle Upper Arm Circumference (MUAC)	Mother-child interaction
Weight-for-age	Developmental track
Appetite and feeding technique	Ability to feed
Oedema (fluid retention)	Muscle tone and posture
HIV status	Vision and hearing

6 LANGUAGE DEVELOPMENT AND AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC)

Augmentative and alternative communication (AAC) has direct bearing on at least four of the developmental disabilities discussed in this manual: ASC, CP and visual and hearing disabilities. **Little or no functional speech (LNFS)** is associated with three of these disabilities. LNFS refers to the absence or limited ability for verbal communication of some children with disabilities. AAC is the tool to address LNFS. Being equipped with AAC, children with LNFS are empowered to communicate and optimal development, self-sufficiency and social participation are promoted in the long run. Children who have speech and/or communication difficulties do not necessarily have marked intellectual and/or learning challenges such as ID and SLD.

Learnt helplessness is established among children with disabilities in early childhood and maintained with time if they are not empowered while the development of language and communication is unfolding. This exacerbates a 'passive acceptant' attitude towards disability. While some environmental adjustments may be made to assist children to 'live with' (their) impairment, they are not age-appropriately equipped for optimal independent functioning. Self-expression and participation in communication are essential prerequisites for social adjustment and cognitive development. Children with visual disabilities rely on communication in Braille as well as other forms of AAC support.

Communication can be described as the purposeful sharing of meaning. A distinction is made between verbal and nonverbal communication. **Verbal communication** refers to making use of word symbols to impart meaning, while **nonverbal communication** employs pictures, drawings and other line symbols to convey meaning. Speech supported by gestures is generally the most comprehensive mode of communicating meaning.

AAC is a broad variety of strategies (primarily non-verbal in nature) that can be used to aid the communication efforts of an individual with little or no functional speech, thereby supplementing (augmenting) speech or in a few select cases becoming a complete alternative to speech. (Bornman & Tönsing 2011: 188)

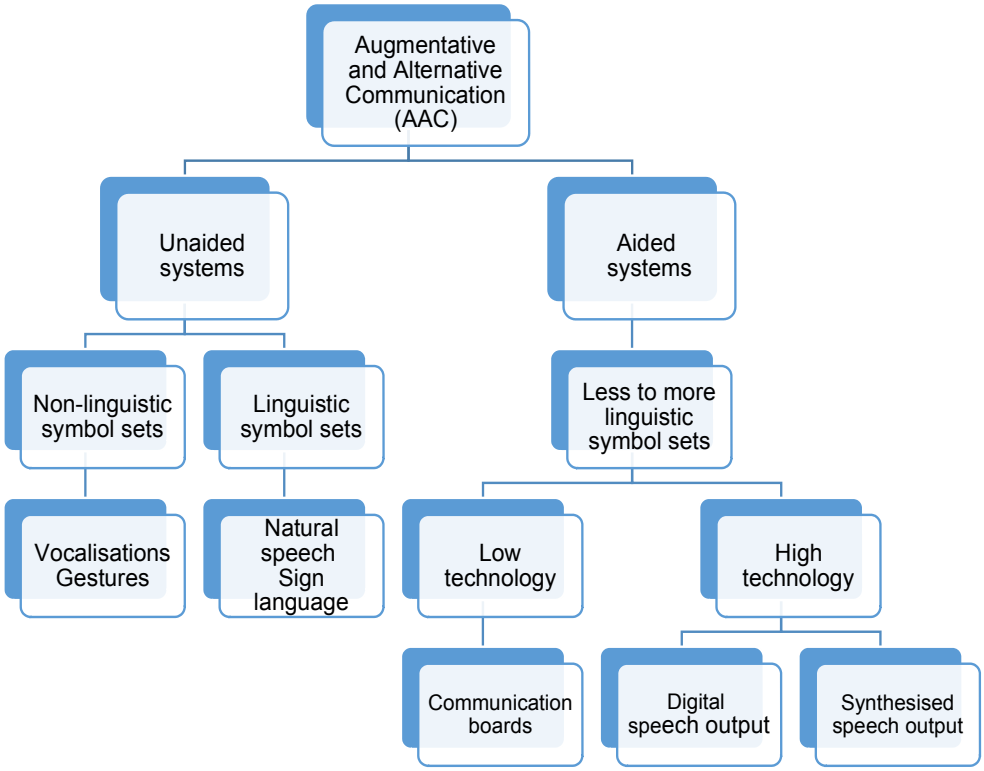
The second function of AAC is to **promote the understanding of meaning** conveyed through spoken language. A very pertinent example is the use of **social stories** to assist children with autismin daily functioning. Social stories do not only guide children towards appropriate behaviour in the social context, they also assist children with autism to interpret their relational contexts, in light of their varied development of ToM.

The Social Story

Elements of the social context guide the nature of communication among parties. Children (and adults) with ASC find it hard to 'read' the social cues embedded in relational situations. Consequently, in order to meet the expectations of responding appropriately, understanding of the social setting is required. *The Social Story* – an augmentative communication tool developed by Carol Gray – has proved to have some positive effect in this regard. Generic social stories are developed for a variety of situations and are available online. These stories can be useful to teach new routines and/or rules. For example, during the Covid-19 pandemic, children are taught about wearing masks and social distancing.

Alternatively, a specific social story is composed for a particular child – either in preparation for an unfamiliar event or as support for coping with challenging personal circumstances. The individualised story is written to address the idiosyncratic issues of the particular child with ASD, keeping in mind her/his personal abilities and developmental needs. For example, when a child has to go to hospital for an EEG examination, the story refers to the actions of specific people such as the parents, doctors and caregivers and appropriate details about the expected procedure and recovery thereafter.

Figure 10: Systems of augmentative and alternative communication (AAC)



AAC is categorised as **unaided** or **aided,** on the basis of the presence or absence of technology during communication. **Sign Language** is an example of unaided AAC and aided AAC ranges from low-tech aids such as communication boards and books to high-tech aids such as synthesised speech. (Figure 10)

The choice of AAC system depends on the individualised developmental needs of the child regarding communication. **High technology (high-tech) aids** refer to assistive devices that require a power source which l**ow technology (low-tech) assistive devices** do not. Both have advantages and disadvantages.

The **cognitive demand** on the user has to be taken into consideration when selecting the appropriate AAC. e.g., a speech generating device (SGD) and picture exchange (PE) rely on recognition memory and therefore less working memory capacity while manual signs (MS) requires recall memory and more working memory to be effective.

Table 7: Comparison of low-tech and high-tech AAC aids

CHARACTERISTIC	LOW-TECH	HIGH-TECH
Cost	Affordable	Difficulty in grasping objects
Design / development of features	Relatively easy Limited pre-determined vocabulary Situation specific Reliant on nouns No feedback for user	Information technology More extended vocabulary Modifiable Language options Auditory feedback for user
Application	Physical communication partner Without clinical and technical support In demanding environments and hi-tech failure	Communication over long distance
Demand on user	No motor pattern learning Navigation sometimes challenging if levels-based	Reach automaticity / motor patterns
Power source	No power source	Mains Rechargeable battery pack
Weight	Not applicable	Can be heavier

7 EARLY IDENTIFICATION AND INTERVENTION

7.1 Namibian Healthcare system

> It is not just mere distance, but it is also difficulty of travel as well as availability of specialized services that is a problem in Namibia's rural areas.
> Van Rooy et al (2012: 764)

The cost of transport to a health facility in Namibia is often prohibitive for impoverished families. If the only option is to access primary healthcare by foot, it is of little advantage that health facilities are within a 10 km radius from 76% of Namibian households. For a parent or caregiver to cover this geographical distance over uneven terrain, pushing a child in a wheel chair or by carrying them, is not only time-consuming, but also physically exhausting. Primary healthcare (PHC) clinics do not operate on appointments, so waiting time can be lengthy and after the consultation, the same demands are repeated for the journey home. Alternatively, PHC services rendered by mobile clinics in rural communities have been found to be mostly sufficient, even for vulnerable children.

The competency of healthcare workers at clinics has also come into question.

Some parents or caregivers believe that advanced expertise is required to render services to persons with disabilities. They also rely on PHC staff to be knowledgeable of what constitutes the best interests of their children in order to make the necessary referrals.

Other challenges that arise in consultations are language differences between service providers and parents or caregivers and the health workers' seemingly 'blunt' attitude toward child patients. Parents or caregivers are entitled to information about their children and the necessary steps for intervention. They have also expressed frustration that medicine and/or auxiliary aids are not available for dispensary at the clinics.

Rehabilitation is extremely important for people with disabilities as it utilizes strategies and techniques focused on restoring the useful life of people. Rehabilitation helps the body achieve normal daily functions. In almost all of the rural clinics and regardless of the type of disability, people living with disabilities complained of lack of rehabilitation.

South African children younger than five years of age mostly come into contact with service providers that are linked to the public health sector, while multidisciplinary outreach teams based at schools for learners with specialised needs are potentially positioned to provide guidance and education to their parents and caregivers. Services for young children with ASD and ADHD, as well as pre-schoolers with other mental health conditions and needs that are trauma-related, should be made available, where possible.

With a view to implementing a protocol for Early Childhood Intervention (ECI to address developmental delays and disabilities, the following procedure may be helpful to establish regional developmental clinics:

- Evaluate present developmental monitoring protocols and practices;
- Identify a 'champion' to prioritise the establishment of a core multidisciplinary team;
- Undertake a detailed study of the way such a system can be implemented;
- Map the work system;
- Identify external support systems (for instance CBR programmes and therapists in private practice);
- Plan to include all staff; and
- Develop a method to systematically and continuously collect and share information about the process.

Primary Healthcare in Namibia

Before gaining independence from South Africa in 1990, Namibia's healthcare system reflected a traditional medical model, which focussed mainly on hospital-based and curative services. Health services were generally poor, and income inequality in Namibia was extreme, as was inequity in access to health services. In response, the newly formed independent government of Namibia made a commitment to health as a fundamental human right and integrated racially divided communities into one healthcare system. Within a few years, the national leadership at the Ministry of Health and Social Services (MoHSS) began reforms to focus on transitioning to a system based on a central role for primary healthcare (PHC).

7.2 Namibian ECD system

Inclusion of very young children with disabilities in the ECD system has been challenging. **Physical access** to spaces of learning is required, as well as **developmentally appropriate accommodation** within the learning environment to ensure their active participation. An informative study in this regard revealed inter alia the challenges faced in setting up a functional system for service provision in Namibia.

Namibian ECD centres and inclusion

During 2016-2017 the Office of the First Lady of Namibia and UNICEF, in collaboration with the University of Namibia Multi-Disciplinary Research and Consultancy Center, conducted a needs assessment study in eight regions of Namibia, involving 32 ECD centres of the 2934 ECD centres registered at the MGECW.

The sampling criteria were rural remoteness, impoverished community and under resourced facility. Thirty-two caregivers and 10 community members at each fieldwork site participated. Three groups were formed for data analysis: (A) school premises / closer to urban area, (B) informal settlement / corrugated-iron structure and (C) impoverished rural / mud structure.

Educarer qualifications ranged from secondary (Grade 10) to tertiary level (Diploma in Education). Fourteen educarers (44%) were certified through attendance of the seven weeks ECD Basic Course Curriculum. A total of 1035 pre-schoolers participated through class observations.

The researchers noted that 4 children in Community C were found to have some form of disability but the support offered to those children was limited to identifying them and making appropriate referrals for expert assessment and treatment. None of the centers were equipped with the necessary materials for these children. In addition, the caregivers advised the affected community members to register vulnerable children with the MGECW in order for them to obtain the necessary support services.

The majority of pre-schoolers in Namibia do not yet have access to a basic standard of ECD. Additionally, for many who are able to access this basic standard, accommodations are not adequately made and their right to participation is therefore not met. The principle of participation is not synonymous with engagement. This difference can manifest in early childhood. The importance of the role of the educarer and peers in facilitating engagement in the learning process in the preschool years is highlighted.

Pre-primary education includes school readiness as well as the transition between preschool and foundational education. There is a double benefit associated with attending ECD facilities for at risk children and children with disabilities. Firstly, children enjoy the typical benefits of **early skills mastery** associated with developing school readiness. Additionally, existing **barriers to learning** are addressed timeously within the window of opportunity for them to benefit optimally from formal schooling. The **adapted theory of change for school readiness** is a remarkable framework for a holistic and integrated approach to Namibian Inclusive early childhood development (IECD). The Side by Side Early Intervention Centre and the CLaSH Preschool are complimentary to this approach. (see Figure 11)

Side by Side Early Intervention Centre, Windhoek

Side by Side is a day care and early intervention centre. It is a non-profit organisation serving families of children with specialised needs.

Association for Children with Language, Speech and Hearing Impairments (CLaSH) Preschool, Windhoek

The preschool education programme is specifically designed for deaf children. The programme is followed at the CLaSH preschool and day care unit.

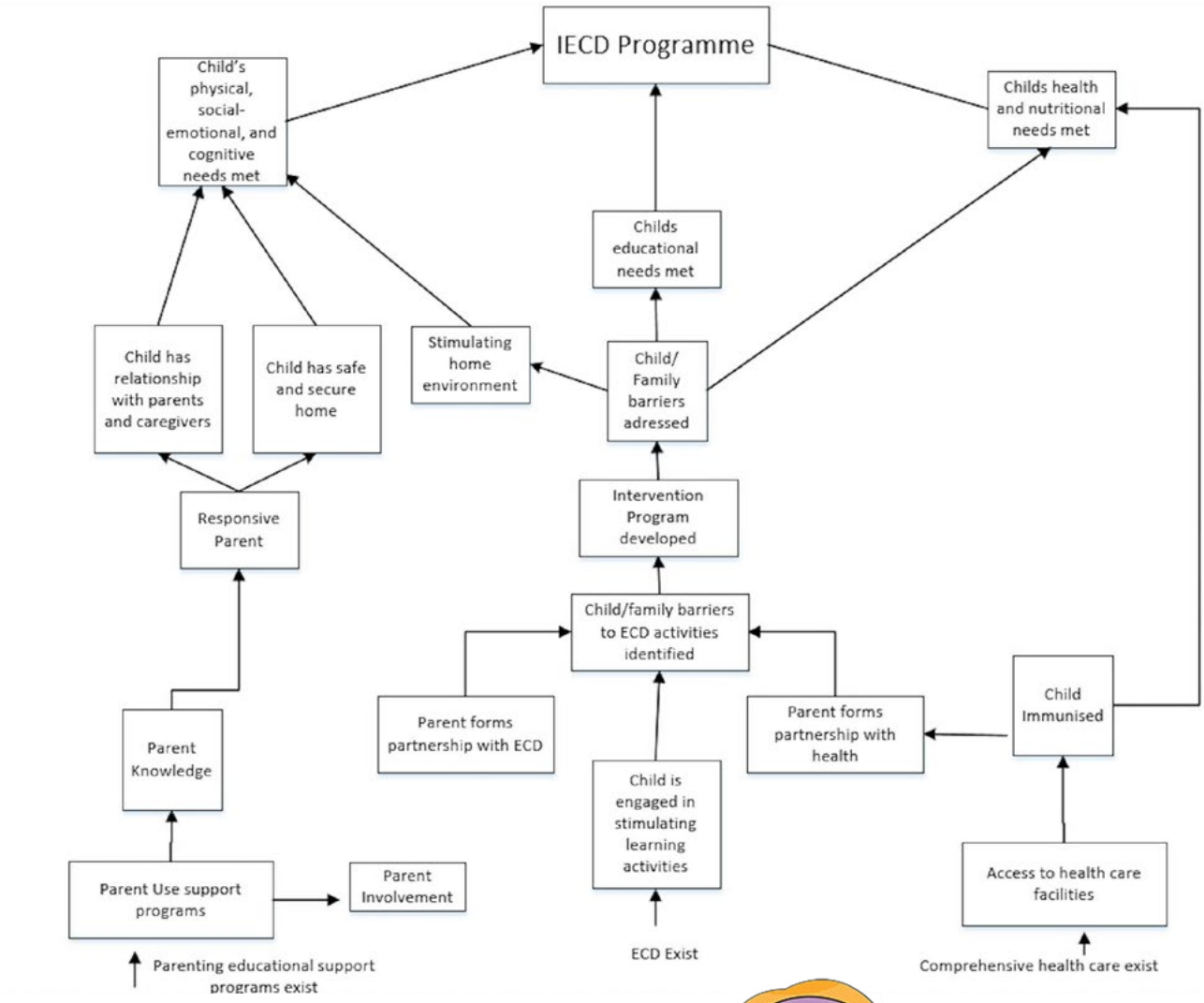
Their mission is to:

- facilitate development towards equal opportunities for children with language, speech and hearing impairments
- ensure equal access to education, training and other facilities
- promote services to meet these children's special needs as early as possible.

The focus is on personalised interventions by specialised teachers and therapists. Specific services during the preschool stage are very important because this is the window period for speech and language development.

CLaSH has formed a support network for parent empowerment and training of professionals. They also provide resources to other schools.

Figure 11: Theory of change for school readiness



According to the proposed IECD model, **the family, and the educare / pre-primary and healthcare systems form a partnership** in assisting pre-schoolers to attain school readiness. The groundwork for this approach is laid when all Namibian pre-schoolers (also those living in rural areas), have access to a functional ECD system and in tandem, efficient healthcare structures. In this scenario, parents or caregivers also actively participate in their children's development.

In functional ECD settings, trained staff utilise developmentally informed curricula and learning materials for young children's preschool development. In efficient healthcare systems, young children's health, physical development and nutritional needs are monitored and sufficient expertise and technology are available if intervention is required. Lastly, the active involvement of parents and caregivers is supported by means of guidance and training in early childhood development.

The early identification of barriers that hamper or prevent optimal benefit from learning, and the provision of appropriate intervention in order to address these challenges, are central to children's eventual readiness for formal schooling. Personal barriers that can deter children from optimal development include neurodevelopmental delays or disabilities associated with a range of impairments.

Children grow up in families and families are embedded within a cultural context. Apart from personal challenges, children can also be unfavourably affected by obstructions related to the family system. The **impact of poverty** can be far-reaching – unhealthy living conditions, acute or chronic malnutrition and parents' limited agency with regards to securing required services and utilising available services often stand in the way of children actualising their full learning potential.

Superstition can hinder young children from enjoying learning opportunities. Stereotyping and societal prejudice can pose an obstacle for parents or caregivers in supporting their children with their neurodiverse development.

Early childhood is the period during which disabilities are usually identified and the impact on children's well-being and development recognized. Young children should never be institutionalized solely on the grounds of disability. It is a priority to ensure that they have equal opportunities to participate fully in education and community life, including by the removal of barriers that impede the realization of their rights. Young disabled children are entitled to appropriate specialist assistance, including support for their parents (or other caregivers). Disabled children should at all times be treated with dignity and in ways that encourage their self-reliance. (General Comment 7,para 36 (d) (UNICEF 2006)

7.3 Protocol

The **Community Based Rehabilitation (CBR)** programme was developed by the Ministry of Health and Social Service (MoHSS) to promote quality of life for persons with disabilities and their families in Namibia. According to the CBR document, the protocol consists of the following phases:

- screening;
- assessment (where applicable); and
- referral and monitoring.

A screening tool for two age groups (0 - 17 years and 18+ years) was compiled for this purpose, as well as individual assessment and referral forms.

Subsequent to identification of needs related to an impairment / health condition, the referral form is used to refer the person to appropriate service providers.

The following professions are associated with potentially rendering services as part of a multidisciplinary team:

- physiotherapy,
- occupational therapy,
- orthopaedic technology,
- social work, and
- health care.

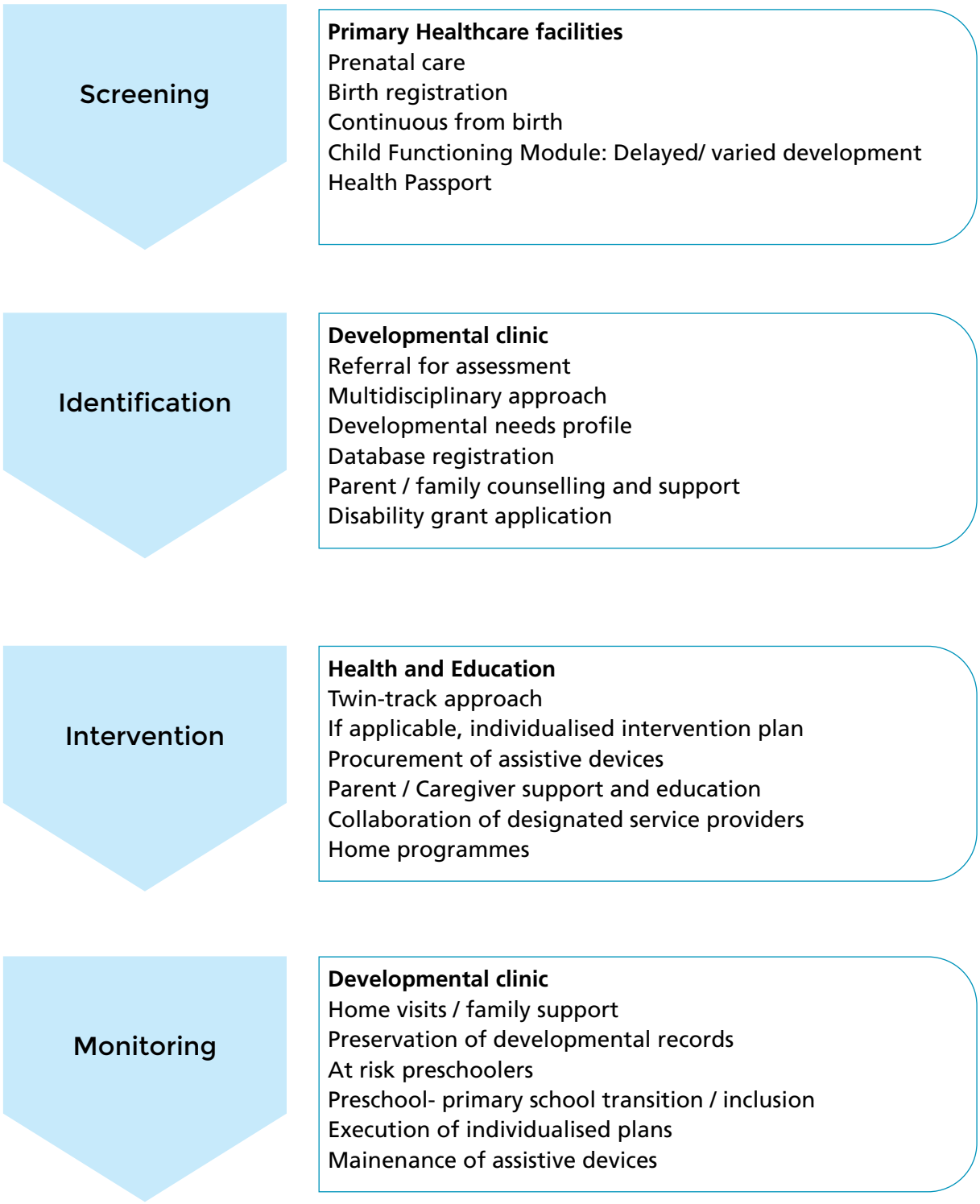
The referral form has a section which is completed by the service provider to whom the client was referred, to indicate the outcome of the consultation. A copy of the referral form is also given to the client.

CBR workers provide continuous support to clients and their families with home visits, and also monitor follow-up service delivery. Another function of CBR workers is to identify children with developmental delays who have not been formally assessed before.

The protocol for early identification and intervention services to children in early childhood is informed by the CBR framework. While there are key services associated with service delivery to children with developmental delays and disabilities, multidisciplinary teams allow coordination of service provision from the fields of healthcare and allied therapies, education, psychology and social work.

According to the 'transdisciplinary model,' members of the multidisciplinary team are flexible in terms of the roles they take with a view to rendering **family-centred services**. This flexibility is particularly relevant for service provision in rural areas. (Appendix 4)

Figure 12: Protocol for ECI service delivery in Namibia



7.3.1 Monitoring

Generally speaking, **monitoring** is a continuous process within the child healthcare system, spanning the full developmental period from conception to the age of majority. (Figure 13)

Figure 13: Developmental monitoring

Pregnancy	Birth	1 year	2 years	3 years	4 years	5 years	6 years
Mother's (mental) health Rubella HIV/ STD	Low Apgar Low birth weight Jaundice	Iron deficiency					

The developmental monitoring process consists of the following activities:

- responding to a parent or caregiver's concern about her/his child's development;
- establishing and maintaining a formal record of the child's developmental history;
- making observations of the child that are informed and reliable;
- identifying relevant vulnerability, resilience and protective factors;
- keeping accurate records of the process and its findings; and
- collaborating with other professionals, by sharing information and obtaining their (in)formal input.

Developmental surveillance (often labeled 'monitoring' by non-medical professionals) is an information gathering process that is flexible, longitudinal, continuous and cumulative. Developmental surveillance/monitoring is completed by a health care professional (and) can be unstructured or structured. If structured, the health care provider incorporates the use of a developmental screening tool (that has strong evidence of reliability and validity) into the developmental surveillance/monitoring process. Conversely, unstructured surveillance /monitoring would be guided by clinical impression or use of a tool that does not have evidence of validity or reliability (e.g use of a checklist or developmental milestones). (Vargas-Barón 2019: 99)

The Care for Child Development Intervention (CCDI) was developed by the World Health Organisation (WHO) and UNICEF as a systematic, cost-effective strategy to promote the health and development of young children that can be applied across a variety of public healthcare settings within resource limitations.

The WHO publication *Caring for the Child's Healthy Growth and Development (2015)* aims to specifically equip healthcare workers to provide basic preventative services. Sections of these ECI programmes were incorporated in the latest version of the Health Passport: feeding recommendations, care during illnesses such as diarrhoea and TB, playing and communicating with the infant and health education.

In Namibia, the child's **Health Passport** is a key document – it records the child's developmental history, current activities pertaining to assessment, and future activities of intervention and monitoring.

The Health Passport

The first page of the Health Passport reads as follows:

This passport is to be used by parents, guardians and health care providers to monitor and promote health, growth, and development of the child.

This is the main record of the child's health growth and development. This booklet contains recommendations for feeding and caring for the child at different ages: as a child grows, their needs change.

Therefore, keep it in a safe place and carry it with whenever the child visits:

- a health centre (whether it is for a well-baby visit or because of illness)
- a doctor or other health care provider
- a hospital outpatient and in-patient department or emergency department
- any other health appointment.

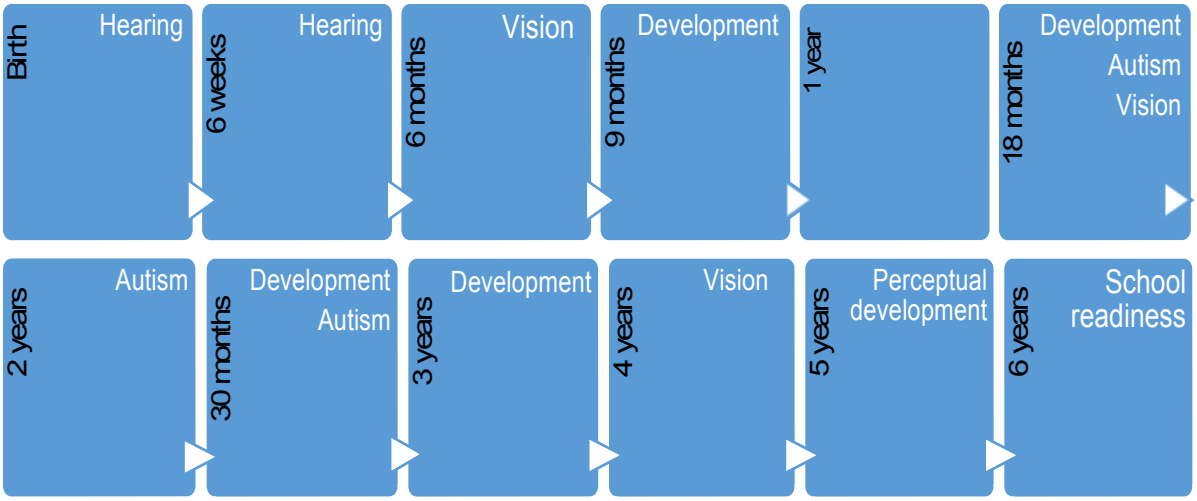
The growth charts in this document are adapted from WHO growth standards.

With reference to children at risk and those with identified disabilities, monitoring also entails keeping track of their developmental progress in light of limitations and challenges. Their right to developing their full potential is protected making it possible for them to step into the adult world as skilled individuals.

Policy makers should ensure that, once a child with a developmental delay or suspected disability receives a positive screening, they will remain in the system until they can benefit from intervention.

(Limited) community resources should be organised in such a way that services are not duplicated and provision goes uninterrupted. Particularly relevant to the preschool group is keen observation of the transition between pre-school education and formal schooling within the inclusive education system.

Figure 14: Developmental screening intervals



7.3.2 Screening

General health screening according to the American Academy of Pediatrics (AAP) guidelines[59] includes regular screening at set intervals for autism. This also pertains to hearing, according to the universal newborn hearing screening. Routine schedules that are inclusive are particularly useful in settings in which parents are unable to access services easily, for example as a result of poverty. The advantage of **scheduled screening** lies in earlier detection of developmental challenges that subsequently can already be addressed well before the time of school entry – young children who present with less obvious or "non-severe" disabilities often remain undetected otherwise.

Alternatively, screening will also be done when a parent or caregiver raises a specific concern during a child's visit to a healthcare facility. (Figure 14)

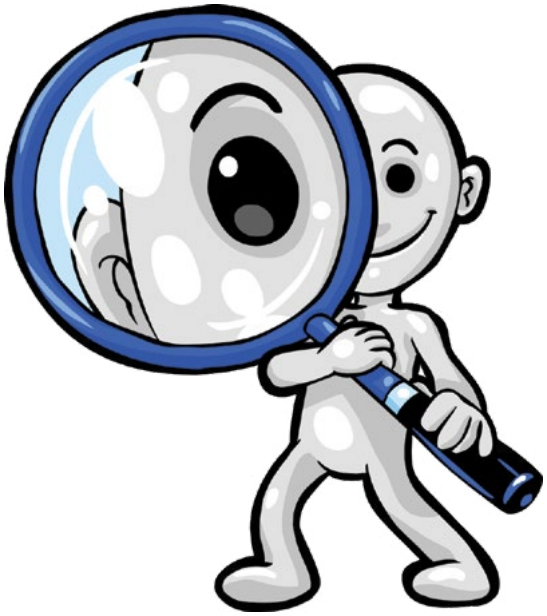
Developmental screening tools are standardised or norm-referenced.[60] This means an opinion on whether a young child's development is significantly delayed or varied is based on a comparison with peers of a similar age.

The Child Functioning Module (CFM) was developed by UNICEF and the Washington Group of Disability Statistics for the improvement of data collection on disability. It is aligned with UNCRPD and the ICF-CY and aims to move beyond stigmatising labels and to focus on the dynamic continuum of "children's actual experiences and the difficulties they encounter in performing daily activities."[61] It has been approved as a low-cost general screening tool to be utilised in under-resourced communities. (Appendix 1)

The CFM is considered to be quick and easy to administer with parents and caregivers and has adequate sensitivity (with disability detected) and specificity (without disability confirmed) for

a screening instrument. Two questionnaires were developed – one for the age group two to four years, and the other for the age group five to 17 years. The following broad domains are covered: vision, hearing, motor development, communication, learning, affect and behaviour. **A positive screening requires a referral for further investigation.** (Appendix 2)

> Developmental screening is the process by which a developmental screening tool (with evidence of reliability, validity and psychometrically-sound cutoffs based on data from a normative sample) is administered, scored, and used to facilitate a discussion with the parent to determine follow-up action. Developmental screening assesses child development across multiple domains (e.g., gross motor, fine motor, communication, problem-solving, personal social) and is typically parent-completed, either independently or with support from trained personnel. (Vargas-Barón 2019: 98)



7.3.3 Identification

A positive screening for significantly varied and/or delayed development is followed by an **assessment**. The sooner a developmental delay or disability is identified, the sooner intervention can follow, and optimal development promoted.

Identification forms part of a comprehensive developmental assessment of health status, personal circumstances and environmental context. The developmental assessment is a process designed to deepen the understanding of a child's competencies and resources, and of the caregiving and learning environments most likely to help a child make fullest use of his or her developmental potential.

With identification of a developmental disability, the child's needs regarding specialised care are also looked at and integrated into an **individualised developmental profile**. (Appendix 3)

The developmental profile is created for the purpose of **planning interventions** and for **monitoring progress**. The child's ecosystemic context is included in the developmental assessment and is examined both objectively and subjectively. Besides contemplating what is objectively (or generally) known about the ecological context of the child's family; the child's household, neighbourhood and community are also subjectively (or specifically) evaluated in terms of basic facilities and resources.

While in some situations identification of developmental delay or disability is straightforward, there are other instances in which the identification process is more complex and may take time due to being synchronised with special markers that unfold during the developmental course. For example, the identification of CP may be direct by applying the GMFCS classification. Or, once hearing loss is identified, the nature of amplification, level of AAC and provision of inclusive education can be determined.

Alternatively, 'easy' identification is generally not the case with very young children with autism. When identification takes time due to various factors at play, it serves the interest of the young child to formulate a 'working diagnosis' in the meantime. Identification on the basis of speculation underpins the importance of conducting a thorough developmental assessment with a view to effective intervention. In general, if neurodevelopmental challenges are anticipated on the basis of a developmental profile, intervention can **prevent secondary issues** that could turn into disability.

ASC: Early identification and intervention

The appeal for early identification of ASC and (even on account of a suspicion) its intervention, is strongly supported by the benefit pre-schoolers reap from specialised intervention services at an early stage of language and communication development. For example, a positive relationship has been found between fluent speech at the age of five years and developmental areas related to school and social relationships at a later stage.

Barriers to early identification of ASC are twofold:

- Screening instruments are not that reliable in detecting ASC at an early age.
- The variation among neurotypical two- and three-year-olds in terms of developmental markers complicates early identification.

Vigilant monitoring of infants' development and in particular **early developmental markers for communication** is therefore required. Effective assessment entails compiling individualised profiles with the involvement of the child's family members in meeting her/his developmental needs. Intervention includes parent training to facilitate developing the pre-schooler's language, communication and social responsiveness development.

Much research has still to be done with regards to constructing a phenotypical base for reliable identification of ASD in SSA. The marked non-verbal presentation of ASD in SSA is not seen as part of the phenotype, but rather ascribed to the implications of late identification and intervention. Although there are prospects for developing appropriate screening and diagnostic tools for ASD in SSA, instruments with confirmed validity are not available yet. Moreover, a body of research on effective intervention does not yet exist.

From a comprehensive scoping review of research articles on ASD in SSA published until October 2016, the following perspectives of families emerged:

Raising a child with ASD is accompanied by financial and marital strain, and parents tend to disregard their personal needs.

Children find it hard "fitting in" at educational facilities, and therefore the approach to education should not only be specialised but also individualised.

The absence of a physical marker of disability in their child causes people to blame the parents for the child's 'poor behavior', and as a result, the family is isolated from their community. Parents need a thick skin to stand up for the rights of their child.

For various reasons, the administration of conventional psychometric tests for assessment is a contentious issue. When a narrow approach to assessment is taken, the emphasis is on test results. However, often the statistical properties of tests (e.g., reliability[62] and validity[63]) compromise the relevance of findings and/or the logic behind conclusions made upon administration.

It is expected that very young children will be linguistically proficient only in their mother tongue. In heterogeneous societies of multiple cultures and rich variation of language, selection of suitable psychometric tests is very difficult (if not impossible), due to the absence of standardised norms. Further, test scores as the outcome of static (as opposed to dynamic) testing have little to offer regarding pointers for intervention.

Assessment measures have to comply with three criteria:

authenticity

1. Procedures have to be **authentic.** The young child's general functional capabilities related to everyday routines should be the focus of observation.

utility

2. The purpose of assessment is **utility** or effectiveness. The young child's capabilities are to be identified with a view to planning interventions and subsequent evaluation of intervention outcomes.

universality

3. It is expected that assessment measures are **universal,** i.e., applicable to all children, also to those with functional limitations.

Assessment content and procedures must be functional and flexible enough to enable all children to demonstrate their capabilities via multiple response modes. Essentially, functional assessments are conducted within the natural environment. Personal functional competencies are identified for planning programmes and support, and the child's progress is monitored during intervention.

Various studies recommend utilising the ICF-CY (2007) for identification and planning of intervention. **The ICF system is specifically applicable for disability grant applications in Namibia, considering the observation that state doctors do not always apply eligibility criteria consistently.**

7.3.4 Intervention

When children are referred to expert therapists to address the developmental delays or disabilities, they gain access to habilitation and rehabilitation services. Several health conditions require a multidisciplinary approach to effective intervention. Primary healthcare, physiotherapy, occupational therapy, speech-language therapy and (educational) psychology are usually represented in the basic multidisciplinary team. However, collaboration by other disciplines may also be required depending on the child's specific developmental needs.

In Namibia, the role of the social worker in the child disability field should not be underestimated While the child's Health Passport has been deemed suitable during intervention services, a best practice protocol for uniform use of the Health Passport is required to elicit efficient communication and effective collaboration. (Appendix 5)

Families of children with ASC require additional support but this can equally be applied to families of children with other developmental disabilities.

> Raising a child with special needs places extra demands on families: financially, emotionally and logistically... (W)e suggest that our current service delivery system might place parents in the difficult position of choosing between caring for a sibling and ensuring that their child with ASD accesses appropriate services to reach their full developmental potential. To complement this model, parents may need additional supports to enroll (sic) and maintain services for their children. Karp et al (2018: s285)

It is crucial that parents and/or caregivers receive additional support when needed. They fulfil a pivotal role in terms of professional service provision to the child in low resource settings, and so not only have to be involved, but also trained, as members of the intervention team. In order to achieve optimal impact, intervention strategies taught to parents and caregivers have to be realistic and attainable.

7.4 Service delivery

Whether in an individual capacity or as members of a multidisciplinary team, qualified professionals regulated by their respective professional boards are bound to professional and ethical conduct during service delivery. On the one hand, the best interest of the young child who is developmentally vulnerable is of primary concern, but due to the child's minority status on the other hand, the rights of her/his parents as custodians are of equal relevance. Parents' and caregivers' right to human dignity, access to information, autonomy and privacy are important in this regard.

Parents' rights

- **Human dignity**

Human dignity refers to every parent or caregiver's inherent value and worth as a member of society. This is linked to her/his personal freedom and physical integrity.

- **Autonomy**

Autonomy is the opposite of paternalism. By treating [parents and caregivers] as autonomous people, [service providers] demonstrate that they respect their dignity of risk – that is, their right to make mistakes. In return, [parents and caregivers] must be able to accept responsibility for their decisions and behaviour, and must in fact do so. Consequently parents and caregivers are entitled to accept or decline recommendations that service providers make on the basis of their autonomy.

- **Access to information**

Competent decision making depends on reliable and sufficient information. An informed decision can only be made when all relevant facts are considered. Every parent or caregiver has the right to a full explanation of the child's health condition and its implications on functioning. If medication is prescribed, its purpose and side effects should be discussed. The parent or caregiver is entitled to know the reason for referral to other service providers, if applicable, and the benefit of suggested interventions.

Concerning early identification of developmental disabilities and delays and subsequent intervention, caution should be exercised against 'inactivity' based on the assumption that ideal services are not fully available.

Consideration should to be given to the following:

- A positive screening outcome should be followed up by a full assessment.
- Identification of delays or disabilities should contribute to practices of inclusion and not exclusion.
- Assessment results indicating the need for intervention have to be followed through with planning as the next step.
- Planning intervention is done in accordance with the availability of services and resources, while considering their potential usefulness.
- Children who were screened and/or assessed have to be monitored to ensure optimal rendering of services.

Thank you

REFERENCES

Aarnoudse-Moens, C.S.H., Weisglas-Kuperus, N., Van Goudoever, J.B. & Oosterlaan, J. 2009. *Meta-Analysis of Neurobehavioral Outcome in Very Preterm and/or Very Low Birth Weight Children.* Pediatrics 124(2): 171-728. doi: 10.1542/peds.2008-2816

ActKnowledge. 2006. *School Readiness Theory of Change Outcomes Framework Only Some City Pennsylvania.* https://www.theoryofchange.org/library/publications/

Adolfsson, M., Sjöman, M. & Björck-Åkesson, E. 2018. *ICF-CY as a Framework for Understanding Child Engagement in Preschool.* Frontiers in Education 3: 36. doi: 3389/feduc.2018.00036

Adolfsson, M., Westerberg, C. & Möller, K. 2014. Everyday Life Situations for School-Aged Children with Severe Disabilities: What are the Goals for the Future. An Exploratory Study. *Journal of Intellectual Disability – Diagnosis and Treatment 2: 21-32.* doi: 6000/2292-2598.2014.02.01.3

African Child Policy Forum (ACPF). 2014. *The African Report on Children with Disabilities: Promising starts and persisting challenges.* Addis Ababa: ACPF.

Ainsworth, P. & Baker, P.C. 2004. *Understanding Mental Retardation: A resource for parents, caregivers and counsellors.* Jackson: University Press of Mississippi.

Allen, A. 2008. *Law and Ethics in Psychology: An International Perspective.* Somerset West: Inter-Ed Publishers.

American Psychiatric Association (APA). 2013a. DSM-5 *Autism Spectrum Disorder Fact Sheet.*

https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/APA_DSM-5-Autism-Spectrum-Disorder.pdf

American Psychiatric Association (APA). 2013b. *Diagnostic and Statistical Manual of Mental Disorders (DSM-5).* Arlington, VA: APA.

Amod, Z. 2013. *A family consultation model of child assessment.* In Laher, S. & Cockroft, K. (Eds.) Psychological Assessment in South Africa. Johannesburg: Wits University Press.

Anderson, V., Northam, E., Hendy, J. & Wrennall, J. 2001. *Developmental Neuropsychology. A Clinical Approach.* New York: Psychology Press.

Andrews, J., Fourie, M. & Watson, R. 2006. *Issues in disability assessment.* In Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Priestley, M. (Eds.) *Disability and social change: A South African agenda.* Cape Town: Human Sciences Research Council (HSRC).

Aneni, E., De Beer, I.H., Hanson, L., Rijnen, B., Brenan, A.T. & Feeley, F.G. 2013. *Mobile primary health care services and health outcomes of children in rural Namibia.* Rural and Remote Health 13: 2380. http://www.rrh.org.au

Araújo, L.A., Silva, L.R. & Mendes, F.A.A. 2012. Neuronal control and digestive manifestations in cerebral palsy. *Journal of Pediatrics (Rio J.) 88(6): 445-464.* doi: 10.1590/S0021-75572012000600003

Archer, N. & Hurley, E.A. 2013. A justice system failing the autistic community. *Journal of Intellectual Disabilities and Offending Behaviour 4(1-2): 53-59.*

Arpino, C., Compagnone, E., Montanaro, M.L., Cacciatore, D., De Luca, A., Cerulli, A., Di Girolamo, S. & Curatolo, P. 2010. *Preterm birth and neurodevelopmental outcome: a review.* Child's Nervous System 26: 1139-1149. doi: 10.1007/s00381-010-1125-y

Asad, A.N., Hand, L., Fairgray, L. & Purdy, S.C. 2013. *The use of dynamic assessment to evaluate narrative learning in children with hearing loss: Three case studies.* Child Language Teaching and Therapy 0(0): 1-24. doi: 10.1177/0265659012467994

Baart, J. & Taaka, F. 2017. *Barriers to Healthcare Services for People with Disabilities in Developing Countries: A Literature Review.* Disability, CBR and Inclusive Development 29(4): 26-40 doi: 10.5463/DCID.v29i4.656

Bagnato, S.J. 2005. The Authentic Alternative for Assessment in Early Intervention: An Emerging Evidence-Based Practice. *Journal of Early Intervention 28(1); 17-22.* doi: 1177/105381510502800102

Bailey, K. 2020. *An Introduction to the Developmental Individual Difference Relationship Based Model – DIR ® /Floortime™.* Ethan Project workshop Mossel Bay South Africa 29 February – 01 March.

Bakare, M.O., Bello-Mojeed, M.A., Munir, K.M., Ogun, O.C. & Eaton, J. 2016. *Neurodevelopmental delay among children under the age three years at immunization clinics in Lagos State, Nigeria – Preliminary report.* Scientific Reports 6(25175): 1-5. doi: 10.1038/srep25175

Bakare, M.O., Munir, K.M. & Bello-Mojeed, M.A. 2014. *Public health and research funding for childhood neurodevelopmental disorders in Sub-Saharan Africa: a time to balance priorities.* Healthcare in Low-resource Settings 2(1559): 1-3. doi: 10.4081/hls.2014.1559

Bakare, M.O., Thunde-Ayinmode, M.F., Adewuya, A.O., Bello-Mojeed, M.A., Sale, S., James, B.O., Yunusa, M.A., Obindo, J.T., Igwe, M.N., Odinka, P.C., Okafor, C.J., Oshodi, Y.O., Okonoda, K.M., Munir, K.M. & Orovwigho, A.O. 2015. *Recognition of Autism Spectrum Disorder (ASD) symptoms and knowledge about some other aspects of ASD among final year medical students in Nigeria, Sub-Saharan Africa.* BMC Research Notes 8(454): 1-8. doi: 10.1186/s13104-015-1433-0

Balakrishnan, S. & Alias, A. 2017. Usage of Social Stories in Encouraging Social Interaction of Children with Autism Spectrum Disorder. *Journal of ICSAR 1(2): 91-97.*

Baldwin, S. & Costley, D. 2016. *The experiences and needs of female adults with high functioning autistic spectrum disorder.* Autism 20(4): 483-495.

Banich, M.T. & Compton, R.J. 2011. *Cognitive Neuroscience Third Edition.* USA: Wadsworth Cengage Learning.

Baron-Cohen, S. 2000. *Is Asperger syndrome / high-functioning autism necessarily a disability?* Development and Psychopathology 12: 489-500.

Baron-Cohen, S. 2009. *The short life of a diagnosis.* The New York Times 09 November. https://www.nytimes.com/2009/11/10/opinion/10baron-cohen.html?_r=0

Bello-Mojeed, M.A., Bakare, M.O. & Munir, K. 2014. *Identification of Autism Spectrum Disorders (ASD) in Africa: Need for Shifting Research and Public Health Focus.* doi: 10.1007/978-1-4614-4788-7_151 http://www.springerreference.com/index/chapterdbid/331260

Berman, R.A. 2008. Psycholinguistics of Text Construction. *Journal of Child Language 35(4): 735-771.*

Borkowski, J.G., Carothers, S.S., Howard, K., Schatz, J. & Farris, J.R. 2009. *Intellectual Assessment and Intellectual Disability.* In Jacobson, J.W., Mulick, J.A. & Rojahn, J. (Eds.) Handbook of Intellectual and Developmental Disabilities. New York: Springer.

Bornman, J. & Tönsing, K. 2011. *Augmentative and alternative communication.* In Landsberg, E., Krüger, D. & Swart, E. (Eds.) Addressing Barriers to Learning. A South African Perspective. Second Edition. Pretoria: Van Schaik.

Botha, P.N. 1989. *Cerebral palsy.* In Kapp, J.A. (Ed.) Children with Problems: An Orthopedagogical Perspective. Pretoria: Serva.

Brilliant, M.H. 2015. *Albinism in Africa: a medical and social emergency.* International Health 7: 223-225. doi: 10.1093/inthealth/ihv039

Cappa, C., Petrowski, N. & Njelesani, J. 2015. *Navigating the landscape of child disability measurement: A review of available data collection instruments.* ALTER, European Journal of Disability Research 9: 317-330. doi: 10.1016/j.alter.2015.08.001

Cederborg, A-C., Danielsson, H., La Rooy, D. & Lamb, M.E. 2009. Repetition of contaminating question types when children and youths with intellectual disabilities are interviewed. *Journal of Intellectual Disability Research 53(5): 440-449.*

Christians, F. 2020. Primary healthcare and family medicine in Namibia. *African Journal of Primary Health Care & Family Medicine.* 12(1): a2242. doi: 10.4102/phcfm.v12i1.2242

Coleman, A., Weir, K.A., Ware, R.S. & Boyd, R.N. 2013. *Relationship Between Communication Skills and Gross Motor Function in Preschool-Aged Children With Cerebral Palsy.* Archives of Physical Medicine and Rehabilitation 94: 2210-2217. doi: 10.1016/j.apmr.2013.03.025

Collins, P.Y., Pringle, B., Alexander, C., Darmstadt, G.L., Heymann, J., Huebner, G., Kutlesic, V., Polk, C., Sherr, L., Shih, A., Stretenov, D. & Zindel, M. 2017. *Global services and support for children with developmental delays and disabilities: Bridging research and policy gaps.* PLoS Med 14(9): e1002393 doi: 10.1371/journal. pmed.1002393

Committee on Practice and Ambulatory Medicine, Section on Ophthalmology, American Association of Certified Ophthalmology, American Association of Certified Orthoptists, American Association for Pediatric Ophthalmology and Strabismus and American Academy of Ophthalmology. 2016. *Visual System Assessment in Infants, Children and Young Adults by Pediatricians.* Pediatrics 137(1): 28-30. doi: 10.1542/peds.2015-3596

Cozolino, L. 2014. *The Neuroscience of Human Relationships: Attachment and the Developing Social Brain* Second Edition. New York: WW Norton.

Crozier, S. & Tincani, M. 2007. Effects of Social Stories on Prosocial Behavior of Preschool Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders.* 37: 1803-1814. doi: 10.1007/s10803-006-0315-7

Currie, I. & De Waal, J. 2013. *The Bill of Rights Handbook.* Sixth Edition. Cape Town: JUTA.

Das, J.P. & Naglieri, J.A. 1996. *Mental Retardation and Assessment of Cognitive Processes.* In Jacobson, J.W. & Mulick, J.A. (Eds.) Manual of Diagnosis and Professional Practice in Mental Retardation. Washington, DC: APA.

Deb, S. 2009. *Epilepsy in People with Mental Retardation.* In Jacobson, J.W., Mulick, J.A. & Rojahn, J. (Eds.) *Handbook of Intellectual and Developmental Disabilities.* New York: Springer.

Denny, L., Coles, S. & Blitz, R. 2017. *Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders.* American Family Physician 96(8): 515-522.

De Vries, P. 2020. *A brain-referenced approach to learning and behaviour.* Paper presented at 5th National Autism & SA-ACAPAP Symposium (Online) Step Ahead on Emotional Regulation. 26 June.

DNA Economics. 2019. *The Cost of Inaction: ECD in Namibia.* Windhoek: Interteam Namibia.

Donahue, S.P. & Baker, C.N. 2016. *Procedures for the Evaluation of the Visual System by Pediatricians.* Pediatrics 137(1): 1-11. doi: 10.1542/peds.2015-3597

Donald, K.A., Kakooza, A.M., Wammanda, R.D., Mallewa, M., Samia, P., Babakir, H., Bearden, D., Majnemer, A., Fehlings, D., Shevell, M., Chugani, H. & Wilmshurst, J.M. 2015. Pediatric Cerebral Palsy in Africa: Where are We? *Journal of Child Neurology* 30(8): 963-971.

Donald, D., Lazarus, S. & Lolwana, P. 2010. *Educational Psychology in Social Context.* Ecosystemic applications in southern Africa Fourth Edition. Cape Town: Oxford.

Durkin, M.S. & Stein, Z.A. 1996. *Classification of Mental Retardation.* In Jacobson, J.W. & Mulick, J.A. (Eds.) *Manual of Diagnosis and Professional Practice in Mental Retardation.* Washington, DC: APA.

Du Toit, L. 1989. *The mentally handicapped.* In Kapp, J.A. (Ed.) Children with Problems: An Orthopedagogical Perspective. Pretoria: Serva.

Eide, A.H., Mannan, H., Khogali, M., Van Rooy, G., Swartz, L., Munthali, A., Hem, K-G., MacLachlan, M. & Dyrstad, K. 2015. *Perceived Barriers for Accessing Health Services among Individuals with Disability in Four African Countries.* PLoS ONE 10(5): e0125915. doi: 10.1371/journal.pone.0125915

Ellis Weismer, S., Lord, C. & Esler, A. 2010. *Early Language Patterns of Toddlers on the Autism Spectrum Compared to Toddlers with Developmental Delay.* Journal of Autism and Developmental Disorders 40: 1259-1273. doi: 10.1007/s10803-010-0983-1

Esterhuizen, A.I., Carvill, G.L., Ramesar, R.S., Kaiuki, S.M., Newton, C.R., Poduri, A. & Wilmshurst, J.M. 2018. *Clinical Application of Epilepsy Genetics in Africa: Is Now the Time?* Frontiers in Neurology 9(267): 1-7. doi:10.3389/fneur.2018.00276

Fahie, C.M. & Symons, D.K. 2003. *Executive functioning and theory of mind in children clinically referred for attention and behavior problems.* Applied Developmental Psychology 24: 51-73.

Fast, D.K. & Conry, J. 2009. *Fetal Alcohol Spectrum Disorders and the Criminal Justice System.* Developmental Disabilities Research Reviews 15: 250-257.

Feuerstein, R., Rand, Y. & Rynders, J.E. 1988. *Don't accept me as I am. Helping "Retarded" People to Excel*. New York: Plenum.

Fisher, R.S., Cross, J.H., D'Souza, C., French, J.A., Haut, S.R., Higurashi, N., Hirsch, E., Jansen, F.E., Lagae, L., Mosh, S.L., Peltola, J., Perez, E.R., Scheffer, I.E., Shculze-Bonhage, A., Somerville, E., Sperling, M., Yacubian, E.M. & Zuberi, S.M. 2017. I*nstruction manual for the ILAE 2017 operational classification of seizure types.* Epilepsia 58(4): 531-542. doi: 10.1111/epi.13671

Forrester, J. 2009. *Working with Children on the Autism Spectrum: Challenges Facing Professionals.* Knysna, South Africa: Workshop 10 October.

Foxcroft, C. & Roodt, G. 2009. *What the future holds for psychological assessment.* In Foxcroft, C. & Roodt, G. (Eds.) Introduction to Psychological Assessment in the South African context Third Edition. Cape Town: Oxford.

Franklin, A., Lund, P., Bradbury-Jones, C. & Taylor, J. 2018. *Children with albinism in African regions: their rights to 'being' and 'doing'.* BMC International Health and Human Rights (18)2: 1-8. doi: 10.1186/s12914-018-0144-8

Franz, L. 2020. *Nurturing social communication abilities to decrease disruptive behaviour in young children with autism.* Paper presented at 5th National Autism & SA-ACAPAP Symposium (Online) Step Ahead on Emotional Regulation. 26 June.

Franz, L., Adewumi, K., Chambers, N., Viljoen, M., Baumgartner, J.N. & De Vries, P.J. 2018. Providing early detection and early intervention for autism spectrum disorder in South Africa: stakeholder perspectives from the Western Cape province. *Journal of Child & Adolescent Mental Health* 30(3): 149-165. doi: 10.2989/17280583.2018.1525386 / Author manuscript 1-23.

Franz, L., Chambers, N., Von Isenburg, M. & De Vries, P.J. 2017. *Autism Spectrum Disorder in Sub-Saharan Africa: A Comprehensive Scoping Review.* Autism Research 10(5): 723-749. doi: 10.1002/aur.1766. Author Manuscript 1-44.

Frazier, T.W., Georgiades, S., Bishop, S.L. & Hardan, A.Y. 2014. *Behavioural and cognitive characteristics of females and males with autism in the Simons Simplex Collection.* Journal of the American Academy of Child & Adolescent Psychiatry 53(3): 329-340.

Garber, B.D. 2010. *Developmental Psychology for Family Law Professionals.* Theory, Application, and the Best Interests of the Child. New York: Springer.

Gerenser, J. & Forman, B. 2009. *Speech and Language Deficits in Children with Developmental Disabilities.* In Jacobson, J.W., Mulick, J.A. & Rojahn, J. (Eds.) Handbook of Intellectual and Developmental Disabilities. New York: Springer.

Gillberg, C. 2009. *The Autism Spectrum.* In Jacobson, J.W., Mulick, J.A. & Rojahn, J. (Eds.) Handbook of Intellectual and Developmental Disabilities. New York: Springer.

Gladstone, M., Mallewa, M., Jalloh, A.A., Voskuijl, W., Postels, D., Groce, N., Kerac, M. & Molyneux, E. 2014. *Assessment of Neurodisability and Malnutrition in Children in Africa.* Seminars in Pediatric Neurology 21: 50-57.

Glauser, T.A. & Loddenkemper, T. 2013. *Management of Childhood Epilepsy.* Continuum 19(3): 656-681.

Global Research on Developmental Disabilities Collaborators. 2018. Developmental Disabilities among children younger than 5 years in 195 countries and territories, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Global Health* 6: e1100-e1121. doi: 10.1016/S2214-109X(18)30309-7

Golzari, F., Alamdarloo, G.H. & Moradi, S. 2015. *The Effect of a Social Stories Intervention on the Social Skills of Male Students With Autism Spectrum Disorder.* SAGE Open October-December: 1-8. doi: 10.1177/2158244015621599

Gould, J. 2017. *Towards understanding the under-recognition of girls and women on the autism spectrum.* Autism 21(6): 703-705.

Gray, C. 2004. Gray's Guide to Bullying. *Jenison Autism Journal* 16(1): 1-74.

Gray, C.A. & Garand, J.D. 1993. *Social Stories: Improving Responses of Students with Autism with Accurate Social Information.* Focus on Autistic Behavior 8(1): 1-10.

Green, D., Chandler, S., Charman, T., Simonoff, E. & Baird, G. 2016. Brief Report: DSM-5 Sensory Behaviours in Children with and Without an Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 46: 3597-3606. doi: 10.1007/s10803-016-2881-7

Greenspan, S.I. & Greenspan, N.T. 2010. *The Learning Tree. Overcoming Learning Disabilities from the Ground Up.* Cambridge, MA: Da Capo Press.

Grieve, K.W. & Foxcroft, C. 2009. *Factors affecting assessment results.* In Foxcroft, C. & Roodt, G. (Eds.) *Introduction to Psychological Assessment in the South African context* Third Edition. Cape Town: Oxford.

Hale, J.B. & Fiorello, C.A. 2004. *School Neuropsychology A Practitioner's Handbook.* New York: Guilford Press.

Hallahan, D.P. & Kaufman, J.M. 1988. *Exceptional Children: Introduction to Special Education* Fourth Edition. Englewood Cliffs, NJ: Prentice Hall.

Haney, J.L. 2016. *Autism, females, and the DSM-5: Gender bias in autism diagnosis.* Social Work in Mental Health 14(4): 396-407.

Happé, F.G.E. 1994. *An Advanced Test of Theory of Mind: Understanding of Story Characters' Thoughts and Feelings by Autistic, Mentally Handicapped, and Normal Children and Adults.* Journal of Autism and Developmental Disorders 24(2): 129-154.

Harty, M. & Alant, E. 2011. *Early childhood development and intervention.* In Landsberg, E., Krüger, D. & Swart, E. (Eds.) *Addressing Barriers to Learning. A South African Perspective.* Second Edition. Pretoria: Van Schaik.

Head, A.M., McGillivray, J.A. & Stokes, M.A. 2014. *Gender differences in emotionality and sociability in children with autism spectrum disorders.* Molecular Autism 5(1): 19.

Henry, L.A. & Gudjonsson, G.H. 2003. *Eyewitness Memory, Suggestibility, and Repeated Recall Sessions in Children with Mild and Moderate Intellectual Disabilities.* Law and Human Behavior 27(5): 481-505.

Hobbs, D. 2019. *Autism – A Parent's Perspective.* Mossel Bay, South Africa: Autism Workshop for Medical and Allied Professionals 13 July.

Hobson, R.P., Lee, A. & Hobson, J.A. 2009. Qualities of Symbolic Play Among Children with Autism: A Social-Developmental Perspective. *Journal of Autism and Developmental Disorders* 39:12-22. doi: 10.1007/s10803-008-0589-z

Hodapp, R.M. & Dykens, E.M. 2009. *Behavioral Effects of Genetic Mental Retardation Disorders.* In Jacobson, J.W., Mulick, J.A. & Rojahn, J. (Eds.) Handbook of Intellectual and Developmental Disabilities. New York: Springer.

Hodge, S.M., Makris, N., Kennedy, D.N., Caviness Jr, V.S., Howard, J., McGrath, L., Steele, S., Frazier, J.A., Tager-Flusberg, H. & Harris, G.J. 2010. Cerebellum, Language, and Cognition in Autism and Specific Language Impairment. *Journal of Autism and Developmental Disorders* 40: 300-316. doi: 10.1007/s10803-0872-7

Hull, L. & Mandy, W. 2017. *Protective effect of missed diagnosis? Females with autism spectrum disorder.* Future Neurology 12(3).

Hull, L., Mandy, W. & Petrides, K.V. 2017. "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders* 47(8): 2519-2534.

Jacobson, J.W. & Mulick, J.A. (Eds.) 1996. *Manual of Diagnosis and Professional Practice in Mental Retardation.* Washington, DC: APA.

Johnson, A M. 1998. *Social Skills Stories: A New Addition to the Curriculum.* The Morning News 10(2): 5-7.

Kamara, E.N., Kasanda, C. & Van Rooy, G. 2018. *Provision of Integrated Early Childhood in Namibia: Are We on the Right Track?* Education Sciences 8: 117. doi: 10.3390/educsci8030117

Kapp, J.A. 1989. The aurally handicapped. In Kapp, J.A. (Ed.) Children with Problems An Orthopedagogical Perspective. Pretoria: Serva.

Karkhaneh, M., Clark, B., Ospina, M.B., Seida, J.C., Smith, V. & Hartling, L. 2010. *Social StoriesTM to improve social skills in children with autism spectrum disorder.* A systematic review. Autism 14(6):641-662. doi: 10.1177/1362361310373057

Karp, E.A., Dudovitz, R., Nelson, B.B, Shih, W., Gulsrud, A., Orlich, F., Colombi, C. & Kuo, A.A. 2018. *Family Characteristics and Children's Receipt of Autism Services in Low-Resourced Families.* Pediatrics 141(s4): s280-s286. doi: 10.1542/peds.2016-4300D

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. & Pellicano, E. 2015. *Which terms should be used to describe autism? Perspectives for the UK autism community.* Autism 1-21. doi: 10.1177/1362361315588200

Kerac, M., Postels, D.G., Mallewa, M., Jalloh, A.A., Voskuijl, W.P., Groce, N., Gladstone, M. & Molyneux, E. 2014. *The Interaction of Malnutrition and Neurologic Disability in Africa.* Seminars in Pediatric Neurology 21: 42-49.

Khair, A.M. & Elmagrabi, D. 2015. *Febrile Seizures and Febrile Seizure Syndromes: An Updated Overview of Old and Current Knowledge.* Neurology Research International. (849341): 1-7. doi: 10.1155/2015/849341

Knutsen, J., Crossman, M., Perrin, J., Shui, A. & Kuhlthau, K. 2019. *Sex differences in restricted repetitive behaviours and interests in children with autism spectrum disorder: An Autism Treatment Network Study.* Autism 23(4): 858-868.

Kodituwakku, P.W. 2009. *Neurocognitive Profile in Children with Fetal Alcohol Spectrum Disorders.* Developmental Disabilities Research Reviews 15: 218-224.

Kodituwakku, P.W. & Kodituwakku, E.L. 2011. *From Research to Practice: An Integrative Framework for the Development of Interventions for children with Fetal Alcohol Spectrum Disorders.* Neuropsychologcal Review 21: 204-233.

Kranowitz, C.S. 2005. *The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder.* Revised and Updated Edition. New York: Skylight Press.

Lamb, G. 2020. *Tracking epilepsy and autism.* Paper presented at 5th National Autism & SA-ACAPAP Symposium (Online) Step Ahead on Emotional Regulation. 27 June.

Lamb, G.V., Green, R.J. & Olorunju, S. 2019. Tracking epilepsy and autism. *The Egyptian Journal of Neurology, Psychiatry and Neurosurgery* 55:55. https://doi.org/10.1186/s41983-019-0103-x

Lai, M-C., Lombardo, M.V., Pasco, G., Ruigrok, A.N.V., Wheelwright, S.J., Sadek, S.A., Chakrabarti & Baron-Cohen, S. 2011. *A behavioural comparison of male and female adults with high functioning spectrum conditions.* PLOS ONE 6(6): e20835.

Lai, M-C., Lombardo, M.V., Suckling, J., Ruigrok, A.N.V., Chakrabarti, B., Ecker, C., Deoni, S.C.L., Craig, M.C., Murphy, D.G.M., Bullmore, E.T. & Baron-Cohen, S. 2013. *Biological sex affects the neurobiology of autism.* Brain 136(9): 2799-2815.

Landsberg, E. 2011. Visual Impairment. In Landsberg, E., Krüger, D. & Swart, E. (Eds.) *Addressing Barriers to Learning. A South African Perspective.* Second Edition. Pretoria: Van Schaik.

Liberator. n.d. *High-tech and low-tech.*
https://liberator.net.au/pub/media/wysiwyg/Types_of_AAC_doc.pdf

Lipkin, P.H. & Macias, M.M. 2020. *Promoting Optimal Development: Identifying Infants and Young Children with Developmental Disorders Through Developmental Surveillance and Screening.* Pediatrics 145(1): e20193449.

Louw, A. & Louw, D. 2014. Middle Childhood. In Louw, D. & Louw, A. (Eds.) *Child and Adolescent Development* Second Edition. Bloemfontein: Psychology Publications.

Love, S.C., Novak, I., Kentish, M., Desloovere, K., Heinen, F., Molenaers, G., Flaherty, S.O. & Graham, H.K. 2010. Botulinum toxin assessment, intervention and after-care for lower limb spasticity in children with cerebral palsy: international consensus statement. *European Journal of Neurology* 17(Suppl 2): 9-37. doi:10.1111/j.1468-1331.2010.03126.x

Lund, P.M. & Gaigher, R. 2002. *An intervention programme for children with albinism at a special school in South Africa.* Health Education Research Theory and Practice 17(3)365-372.

Lund, P.M. & Taylor, J.S. 2008. *Lack of adequate sun protection for children with oculocutaneous albinism in South Africa.* BMC Public Health 8(225): 1-8. doi: 10.1186/1471-2458-8-225

Lynch, P. & Lund, P. 2011. *Education of children and young people with albinism in Malawi.* Field Report for the Commonwealth Secretariat.

http://www.birmingham.ac.uk/research/activity/education/projects/albinism-in-malawi.aspx

Magyar, C.I., Pandolfi, V. & Peterson, C.R. 2009. *Psychoeducational Assessment.* In Jacobson, J.W., Mulick, J.A. & Rojahn, J. (Eds.) Handbook of Intellectual and Developmental Disabilities. New York: Springer.

Malherbe, G. 2012. *Developmental Disorders: Latest Research.* Somerset West, South Africa: Workshop 23 May.

Malherbe, G. 2013. *Autistic Spectrum Disorders.* Somerset West, South Africa: Workshop 24 April.

Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A. & Skuse, D. 2012. Sex differences in autism spectrum disorder: Evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders* 42(7): 1304-1313.

Manno, C.J., Fox, C., Eicher, P.S. & Kerwin, M.E. 2005. Early Oral-Motor Interventions for Pediatric Feeding Problems: What, When and How. *Journal of Early and Intensive Behavior Intervention* 2(3): 145-159.

Manolitsi, M. & Botting, N. 2011. *Language abilities in children with autism and language impairment: using narrative as a (sic) additional source of clinical information.* Child Language Teaching and Therapy 27(1): 39-55.

Mash, E.J. & Wolfe, D.A. 2010. *Abnormal Child Psychology* Fourth Edition. Belmont: Wadsworth.

Mattson, S., Crocker, N. & Nguyen, T.T. 2011. *Fetal Alcohol Spectrum Disorders: Neuropsychological and Behavioral Features.* Neuropsychological Review 21: 81-101.

Maurer, D., Mondloch, C.J. & Lewis, T.L. 2007. *Sleeper effects.* Developmental Science 10(1): 40-47. doi: 10.1111/j.1467-7687.2007.00562.x

McDermott, S., Durkin, M.S., Schupf, N. & Stein, Z.A. 2009. *Epidemiology and Etiology of Mental Retardation.* In Jacobson, J.W., Mulick, J.A. & Rojahn, J. (Eds.) Handbook of Intellectual and Developmental Disabilities. New York: Springer.

McKenzie, J. & Ohanjunwa, C.O. 2017. *Understanding disability i*n Nigeria: A commentary on "Country profile: intellectual and developmental disability in Nigeria". Tizard Learning Disability Review 22(2): 94-98. doi: 10.1108/TLDR-02-2017-0008

McLinden, M., Lynch, P., Soni, A., Artiles, A., Kholowa, F., Kamchedzera, E., Mbukwa, J. & Mankhwazi, M. 2018. Supporting Children with Disabilities in Low- and Middle Income Countries: Promoting Inclusive Practice within Community-Based Childcare Centres in Malawi through a Bioecological Systems Perspective. *International Journal of Early Childhood* 50: 159-174. doi: 10.1007/s13158-018-0223-y

Mei, C., Reilly, S., Reddihough, D., Mensah, F., Green, J., Pennington, L. & Morgan, A.T. 2015. Activities and participation of children with cerebral palsy: parent perspectives. *Journal of Disability and Rehabilitation*. doi: 3109/09638288.2014.999164

Meiring, M. 2014. *Personal communication.* Educational psychologist, Pioneer School for the Blind, Worcester South Africa. 12 June.

Melunovic, M., Hadzagic-Catibusic, F., Bilalovic, V., Rhamanovic, S. & Dizdar, S. 2017. *Anthropometric Parameters of Nutritional Status in Children with Cerebral Palsy.* Mater Sociomed 29(1): 68-72. doi: 10.5455/msm.2017.29.68-72

Messiou, K. 2017. Research in the field of inclusive education: time for a rethink? International *Journal of inclusive Education* 21(2): 146-159. doi: 10.1080/13603116.2016.1223184

Miller, D.C. 2007. *Essentials of School Neuropsychological Assessment.* Hoboken, NJ: Wiley.

Ministry of Health and Social Services. 2014. *Guide to Initiating, Implementing, Monitoring Community Based Rehabilitation.* Windhoek: Social Welfare Services.

Mont, D. 2019. *Childhood Disability and Poverty.* Leonard Cheshire Disability and Inclusive Development Centre Working Paper 25. https://ssrn.com/abstract=3398210 or http://dx.doi.org/10.2139/ssrn.3398210

Murray, J. & Goldbart, J. 2009. C*ognitive and language acquisition in typical and aided language learning: A review of recent evidence from an aided communication perspective.* Child Language Teaching and Therapy 25(1): 31-58.

Namibia Ministry of Health and Social Services (MoHSS) and ICF International. 2014. *The Namibia Demographic and Health Survey 2013.* Windhoek, Namibia and Rockville, Maryland USA: MoHSS and ICF International.

National Autistic Society. 2016. *Diagnosis for Children.* https://www.autism.org.uk/about/diagnosis/children.aspx

Nel, N. 2014. *How to empower children with disabilities to safeguard themselves and to set boundaries.* SAPSAC 15th Annual Conference Pretoria, South Africa 11 November.

Ngula, A.K. 2018. *The information needs of people with albinism in Khomas region, Namibia.* University of Cape Town: Unpublished M Phil Dissertation.

Ntinda, R.N. 2010. *Customary practices and children with albinism in Namibia: A constitutional challenge?* In Ruppel, O.C. (Ed.) Children's Rights in Namibia. https://www.kas.de/c/document_library/get_file?uuid=b6dc0797-15b0-962e-f1bc-46a19ab239f7&groupId=252038

Olivier, G. 2020. *Social Camouflaging Theory: Girls are less likely to be identified with autism.* Contribution to contents of training module draft.

Owens, R.E. 1996. *Language Development: An Introduction* Fourth Edition. Needham Heights, MA: Allyn & Bacon.

Palisano, R., Rosenbaum, P., Bartlett, D. & Livingston, M. 2007. *Gross Motor Function Classification System Expanded and Revised.* CanChild Centre for Childhood Disability Research, McMaster University. https://www.physio-pedia.com/Gross_Motor_Function_Classification_System_-_Expanded_and_Revised_(GMFCS-ER)

Palisano, R.J., Rosenbaum, P., Walter, S., Russell, D., Wood, E. & Galuppi, B.1997. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Developmental Medicine and Child Neurology 45: 113-120.

Panayiotopoulos, C.P. 2006. Epileptic Encephalopathies in Infancy and Childhood. Epilepsy Foundation website. https://www.epilepsy.com/learn/professionals/about-epilepsy-seizures/epileptic-encephalopathies-infancy-and-childhood

Pauw, T. 1989. The visually handicapped. In Kapp, J.A. (Ed.) Children with Problems An Orthopedagogical Perspective. Pretoria: Serva.

PDA Society. 2016. Pathological Demand Avoidance Syndrome. A Reference Booklet for Health, Education and Social Care Practitioners. Revised Edition. PDA Society.

Physiopedia contributors. 2019. Classification of Cerebral Palsy. Physiopedia. https://www.physio-pedia.com/index.php?title=Classification_of_Cerebral_Palsy&oldid=222825.

Prelock, P.J. & Nelson, N.W. 2012. Language and Communication in Autism: An Integrated View. Pediatric Clinics of North America 59(1): 129-145.

Ramey, C.T., Mulvihill, B.A. & Ramey, S.L. 1996. Prevention: Social and Educational Factors and Early Intervention. In Jacobson, J.W. & Mulick, J.A. (Eds.) Manual of Diagnosis and Professional Practice in Mental Retardation. Washington, DC: APA.

Rasmussen, C., Talwar, V., Loomes, C. & Andrew, G. 2008. Brief Report: Lie-telling in Children with Fetal Alcohol Spectrum Disorder. Journal of Pediatric Psychology 33(2): 220-226. doi: 10.1093/jpepsy/jsm069

Reid, S.M., Carlin, J.B. & Reddihough, D.S. 2011. Using the Gross Motor Function Classification System to describe patterns of motor severity in cerebral palsy. Developmental Medicine & Child Neurology 53: 1007-1012. doi: 10.1111/j.1469-8749.2011.04044.x

Richmond, M. 2006. Oral Motor Developmental Milestones. Super Duper Handy Handouts No 122. https://www.superduperinc.com/handouts/pdf/122_OralMotorDevelopmentalMilestones.pdf

Roodt, G. 2009a. *Basic measurement and scaling concepts.* In Foxcroft, C. & Roodt, G. (Eds.) Introduction to Psychological Assessment in the South African context Third Edition. Cape Town: Oxford.

Roodt, G. 2009b. *Reliability: Basic concepts and measures.* In Foxcroft, C. & Roodt, G. (Eds.) Introduction to Psychological Assessment in the South African context Third Edition. Cape Town: Oxford.

Roodt, G. 2009c. *Validity: Basic concepts and measures.* In Foxcroft, C. & Roodt, G. (Eds.) Introduction to Psychological Assessment in the South African context Third Edition. Cape Town: Oxford.

Roodt, G., Stroud, L., Foxcroft, C. & Elkonin, D. 2009. *The use of assessment measures in various applied contexts.* In Foxcroft, C. & Roodt, G. (Eds.) Introduction to Psychological Assessment in the South African context Third Edition. Cape Town: Oxford.

Routh, D.K. 1996. *Intellectual Development.* In Jacobson, J.W. & Mulick, J.A. (Eds.) Manual of Diagnosis and Professional Practice in Mental Retardation. Washington, DC: APA.

Russo, D.C., Dunn, E., Pace, G. & Codding, R.S. 2009. P*ediatric Brain Injury*. In Jacobson, J.W., Mulick, J.A. & Rojahn, J. (Eds.) Handbook of Intellectual and Developmental Disabilities. New York: Springer.

Samuels, A.E., Slemming, W. & Balton, S. 2012. *Early Childhood Intervention in South Africa in Relation to the Developmental Systems Model.* Infants and Young Children 25(4) Author manuscript.

Schachter, M. & Demerath, R. 1996. *Neuropsychology and Mental Retardation.* In Jacobson, J.W. & Mulick, J.A. (Eds.) Manual of Diagnosis and Professional Practice in Mental Retardation. Washington, DC: APA.

Schalock, R.L., Luckasson, R.A., Shogren, K.A., Borthwick-Duffy, S., Bradley, V., Buntinx, W.H.E., Coulter, D.L., Craig, E.M., Gomez, S.C., Lachapelle, Y., Reeve, A., Snell, M.E., Spreat, S., Tasse, M.J., Thompson, J.R., Verdugo, M.A., Wehmeyer, M.L. & Yeager, M.H. 2007. The *Renaming of Mental Retardation: Understanding the Change to the Term Intellectual Disability.* Intellectual and Developmental Disabilities 45(2): 116-124.

Schalock, R.L. & Luckasson, R. 2013. *What's at Stake in the Lives of People With Intellectual Disability? Part I: The Power of Naming, Defining, Diagnosing, Classifying and Planning Supports.* Intellectual and Developmental Disabilities 51(2): 86-93. doi: 10.1352/1934-9556-51.2.086

Schreibman, L., Dawson, G., Stahmer, A.C., Landa, R., Rogers, S.J., McGee, G.G., Kasari, C., Ingersoll, B., Kaiser, A.P., Bruinsma, Y., McNerney, E., Wetherby, A. & Halladay, A. 2015. Naturalistic Developmental Behavioral Interventions: Empirically Validated Treatments for Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 45: 2411-2428. doi: 10.1007/s10803-015-2407-8

Segalowitz, S.J. & Schmidt, L.A. 2005. *Developmental Psychology and the Neurosciences.* In Valsiner, J. & Connolly, K. (Eds.) Handbook of Developmental Psychology. London: SAGE.

Shumba, T.W. & Moodley, I., 2018. Implementation of disability policy framework in Namibia: A qualitative study. *South African Journal of Physiotherapy* 74(1): a400. doi: 10.4102/sajp. v74i1.400

Siller, M. & Sigman, M. 2008. *Modeling Longitudinal Change in the Language Abilities of Children With Autism: Parent Behaviors and Child Characteristics as Predictors of Change.* Developmental Psychology 44(6):1691-1704. doi: 10.1037/a0013771

Sjöman, M., Granlund, M. & Almqvist, L. 2016. *Interaction processes as a mediating factor between children's externalised behaviour difficulties and engagement in preschool.* Early Child Development and Care (online). doi: 10.1080/03004430.2015.1121251

Smith, T., Magyar, C. & Arnold-Saritepe, A. 2002. *Autism Spectrum Disorder.* In Marsh, D.T. & Fristad, M.A. (Eds.) Handbook of Serious Emotional Disturbance in Children and Adolescents. New York: John Wiley.

Sodian, B. & Frith, U. 1992. Deception and Sabotage in Autistic, Retarded and Normal Children. *Journal of Child Psychology and Psychiatry* 33(3): 591-605.

Sparrow, S.S., Cicchetti, D.V. & Balla, D.A. 2005. Vineland-ll Vineland Adaptive Behavior Scales Survey Forms Manual Second Edition. Minneapolis: Pearson.

Sprung, M. 2010. *Clinically Relevant Measures of Children's Theory of Mind and Knowledge about Thinking: Non-Standard and Advanced Measures.* Child and Adolescent Mental Health 15(4): 204-216.

Stanley, G.C. & Konstantareas, M.M. 2007. Symbolic Play in Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 37: 1215-1223. doi: 10.1007/s10803-006-0263-2

Stefanos, G.A. & Baron, I.S. 2011. *The Ontogenesis of Language Impairment in Autism: A Neuropsychological Perspective.* Neuropsychology Review 21: 252-270. doi: 10.1007/s11065-011-9178-6

Stiegler, L.N. 2015. Examining the echolalia literature: Where do speech-language pathologists stand? *American Journal of Speech-Language Pathology* 24: 750-762. doi: 10.1044/2015_AJSLP-14-0166

Stodel, D. 2016. *Treating communication difficulties in autism.* Ethan Project Training Mossel Bay, South Africa 08 October.

Stone-MacDonald, A. 2015. *Identification and Labels for Young Tanzanian Children: An Examination of Labels for Children with Intellectual Disabilities.* DADD Online Journal 2(1): 202-217.

http://daddcec.org/Portals/0/CEC/Autism_Disabilities/Research/Publications/dec2_2015%20DOJ_2.pdf

Storbeck, C. 2011. *Educating the deaf and hard-of-hearing learner.* In Landsberg, E., Krüger, D. & Swart, E. (Eds.) Addressing Barriers to Learning. A South African Perspective. Second Edition. Pretoria: Van Schaik.

Taderera, C. & Hall, H. 2017. Challenges faced by parents in parenting children with learning disabilities in Opuwo, Namibia. *African Journal of Disability* 6: a283. doi: 10.4102/ajod. v6i0.283

Truter, B. 2017. *Introduction to the spectrum of autism: Neurodivergence as opposed to "neuro-disability."* Ethan Project Training Mossel Bay, South Africa 26 June.

Truter, S. 2016. *Memory & Learning in Children.* A Workshop of Applied Neuropsychology. Pretoria: Mindmuzik Media.

United Nations Children's Fund (UNICEF). 2012. *School Readiness and Transitions.* A companion to the Child Friendly Schools manual. New York: UNICEF.

UNICEF & Washington Group on Disability Statistics. 2017. UNICEF / Washington Group on Disability Statistics Module on Child Functioning. UNICEF.

United Nations Educational, Scientific and Cultural Organization (UNESCO). 2019. *N FOR NOSE.* State of the Education Report for India 2019. Children with Disabilities. New Delhi: UNESCO.

Van der Meer, L., Didden, R., Sutherland, D., O'Reilly, M.F., Lancioni, G.E. & Sigafoos, J. 2012. Comparing three augmentative and alternative communication modes for children with developmental disabilities. *Journal of Developmental and Physical Disabilities* 24(5): 451-468.

Van Eeden, R. & De Beer, M. 2009. *Assessment of cognitive functioning.* In Foxcroft, C. & Roodt, G. (Eds.) Introduction to Psychological Assessment in the South African context Third Edition. Cape Town: Oxford.

Van Niekerk, H.A. 2014. *Determining the competency of children with developmental delays to testify in criminal trials.* Rhodes University: Unpublished PhD dissertation.

Van Niekerk, L. 2014. Personal communication. Speech-language therapist, Private Practice George South Africa. 30 July.

Van Rooy, G., Amadhila, E.M., Mufune, P. & Swartz, L., Mannan, H. & MacLachlan, M. 2012. *Perceived barriers to accessing health services among people with disabilities in rural northern Namibia.* Disability & Society 27(6): 761-775. doi: 10.1080/09687599.2012.686877

Vargas-Barón, E., Small, J., Wertlieb, D., Hix-Small, H., Gómez Botero, R., Diehl, K., Vergara, P. & Lynch, P. 2019. *Global Survey of Inclusive Early Childhood Development and Early Childhood Intervention Programs.* Washington, DC: RISE Institute.

Visser, M., Nel, M., Bronkhorst, C., Brown, L., Ezendam, Z., Mackenzie, K., Van der Merwe, D. & Venter, M. 2016. Childhood disability population-based surveillance: Assessment of the Ages and Stages Questionnaire Third Edition and Washington Group of Disability Statistics / UNICEF module on child functioning in a rural setting in South Africa. *African Journal of Disability* 5(1): a265. doi: 10.4102/ajod.v5i1. 265

Wacha, V.H. & Obrzut, J.E., 2007. Effects of Fetal Alcohol Syndrome on Neuropsychological Function. *Journal of Developmental and Physical Disabilities* 19: 217-226.

Walker-Hirsch, L. 2007. *Foundations in Social Development Education and Sexuality Education Techniques.* In Walker-Hirsch (Ed.) The Facts of Life...and More. Sexuality and Intimacy for People for Intellectual Disabilities. Baltimore: Paul H. Brookes.

Weismer, S.E., Lord, C. & Esler, A. 2010. Early Language Patterns of Toddlers on the Autism Spectrum Compared to Toddlers with Developmental Delay. *Journal of Autism and Developmental Disorders* 40: 1259-1273.

Williams, A.E., Guist, J.M., Kronenberger, W.G. & Dunn, D.W. 2016. *Epilepsy and attention-deficit hyperactivity disorder: links, risks, and challenges.* Neuropsychiatric Disease and Treatment 12: 287-296.

Wilmshurst, J.M., Kakooza-Mwesige, A. & Newton, C.R. 2014. *The Challenges of Managing Children with Epilepsy in Africa. S*eminars in Pediatric Neurology 21(1): 36-41.

World Health Organisation (WHO). 2007. *International Classification of Functioning, Disability and Health: Children & Youth version (ICF-CY).* Geneva: WHO.

WHO. 2012. *Developmental Difficulties in Early Childhood.* Prevention, early identification, assessment and intervention in low- and middle-income countries. A Review. Geneva: WHO.

WHO & UNICEF. 2012. *Early Childhood Development and Disability: A discussion paper.* Geneva: WHO.

Winter, S. 2009. *Cerebral Palsy.* In Jacobson, J.W., Mulick, J.A. & Rojahn, J. (Eds.) Handbook of Intellectual and Developmental Disabilities. New York: Springer.

Woolfolk, A. 2010. *Educational Psychology* Eleventh Edition. Saddle River, NJ: Pearson International.

Woythaler, M.A., McCormick, M.C. & Smith, V.C. 2011. *Late Preterm Infants Have Worse 24-Month Neurodevelopmental Outcomes Than Term Infants.* Pediatrics 127(3): e622-e629. doi: 10.1542/peds.2009-3598

Zabow, T. & Kaliski, S. 2006. *Ethical considerations.* In Kaliski, S. (Ed.) Psycholegal Assessment in South Africa. Cape Town: Oxford.

Zigler, E. & Balla, D. 1982. I*ntroduction: Developmental Approach to Mental Retardation.* In Zigler, E. & Balla, D. (Eds.) Mental Retardation: The Developmental-difference Controversy. Hillsdale: Lawrence Erlbaum.

Zwaigenbaum, L., Bryson, S.E., Szatmari, P., Brian, J., Smith, I.M., Roberts, W., Vaillancourt, T. & Roncadin, C. 2012. Sex differences in children with autism spectrum disorder identified within a high-risk infant cohort. J*ournal of Autism and Developmental Disorders* 42(12): 2585-2596.

APPENDIX 1

CHILD FUNCTIONING MODULE (CFM) (UNICEF / WASHINGTON GROUP OF DISABILITY STATISTICS 2016)

Instructions

1. Select the questionnaire according to the child's age.

2. Two response formats are used: dichotomous yes/no and scaled responses. After introducing yourself, explaining the purpose of the measure and establishing rapport, read each question and where applicable, insert the child's name and examples. Ensure that you clarify the instructions and probe for additional information where needed.

3. Mark the answer given by the mother or primary caregiver. Provide positive feedback on responses to enhance participant motivation and participation.

4. Pay attention to the skip patterns of questions. If there is an arrow in the right hand column next to the answer that was selected, it indicates which question is to be read next.

5. "A lot of difficulty" and "Cannot do at all" answers, as well as the "a lot more" on the question on controlling behaviour, deserve further attention as these indicate functional difficulty.

6. Check that all of the information has been completed, the questions have been answered and additional comments or information recorded.

The link to the manual with full instructions on administration is: https://data.unicef.org/resources/module-on-child-functioning-manual-for-interviewers/

The link to the questionnaires is: https://data.unicef.org/resources/module-child-functioning/

CHILD FUNCTIONING (AGE 2-4)		CF
CF1. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE. DOES (*NAME*) WEAR GLASSES?	Yes.....1 No.....2	 2 ☐ CF3
CF2. WHEN WEARING HIS/HER GLASSES, DOES (*NAME*) HAVE DIFFICULTY SEEING? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	 No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	 1 ☐ CF4 2 ☐ CF4 3 ☐ CF4 4 ☐ CF4
CF3. DOES (*NAME*) HAVE DIFFICULTY SEEING? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	 No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF4. DOES (*NAME*) USE A HEARING AID?	Yes.....1 No.....2	 2 ☐ CF6
CF5. WHEN USING HIS/HER HEARING AID, DOES (*NAME*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	 No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	 1 ☐ CF7 2 ☐ CF7 3 ☐ CF7 4 ☐ CF7
CF6. DOES (*NAME*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	 No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF7. DOES (*NAME*) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?	Yes.....1 No.....2	 2 ☐ CF10
CF8. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*NAME*) HAVE DIFFICULTY WALKING? WOULD YOU SAY (*NAME*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF9. WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*NAME*) HAVE DIFFICULTY WALKING? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	 No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	 1 ☐ CF11 2 ☐ CF11 3 ☐ CF11 4 ☐ CF11
CF10. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*NAME*) HAVE DIFFICULTY WALKING? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	 No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	

CF11. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*NAME*) HAVE DIFFICULTY PICKING UP SMALL OBJECTS WITH HIS/HER HAND? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF12. DOES (*NAME*) HAVE DIFFICULTY UNDERSTANDING YOU? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF13. WHEN (*NAME*) SPEAKS, DO YOU HAVE DIFFICULTY UNDERSTANDING HIM/HER? WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF14. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*NAME*) HAVE DIFFICULTY LEARNING THINGS? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF15. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*NAME*) HAVE DIFFICULTY PLAYING? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF16. COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DOES (*NAME*) KICK, BITE OR HIT OTHER CHILDREN OR ADULTS? WOULD YOU SAY: NOT AT ALL, THE SAME OR LESS, MORE OR A LOT MORE?	Not at all.....1 The same or less.....2 More.....3 A lot more.....4	

CHILD FUNCTIONING (AGE 5-17)		CF
CF1. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE. DOES (*NAME*) WEAR GLASSES OR CONTACT LENSES?	Yes.....1 No.....2	 2⇨CF3
CF2. WHEN WEARING HIS/HER GLASSES OR CONTACT LENSES, DOES (*NAME*) HAVE DIFFICULTY SEEING? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	1⇨CF4 2⇨CF4 3⇨CF4 4⇨CF4
CF3. DOES (*NAME*) HAVE DIFFICULTY SEEING? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF4. DOES (*NAME*) USE A HEARING AID?	Yes.....1 No.....2	 2⇨CF6
CF5. WHEN USING HIS/HER HEARING AID, DOES (*NAME*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	1⇨CF7 2⇨CF7 3⇨CF7 4⇨CF7
CF6. DOES (*NAME*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF7. DOES (*NAME*) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?	Yes.....1 No.....2	 2⇨CF12
CF8. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*NAME*) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (*NAME*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	 3⇨CF10 4⇨CF10
CF9. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*NAME*) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (*NAME*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	

CF10. With his/her equipment or assistance, does (*NAME*) have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. [Or insert country specific example]. Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	3⇨CF14 4⇨CF14
CF11. With his/her equipment or assistance, does (*NAME*) have difficulty walking 500 yards/meters on level ground? That would be about the length of 5 football fields. [Or insert country specific example]. Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	1⇨CF14 2⇨CF14 3⇨CF14 4⇨CF14
CF12. Compared with children of the same age, does (*NAME*) have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. [Or insert country specific example]. Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	3⇨CF14 4⇨CF14
CF13. Compared with children of the same age, does (*NAME*) have difficulty walking 500 yards/meters on level ground? That would be about the length of 5 football fields. [Or insert country specific example]. Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF14. Does (*NAME*) have difficulty with self-care such as feeding or dressing him/herself? Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF15. When (*NAME*) speaks, does he/she have difficulty being understood by people inside of this household? Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	

CF16. When (*NAME*) speaks, does he/she have difficulty being understood by people outside of this household? Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF17. Compared with children of the same age, does (*NAME*) have difficulty learning things? Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF18. Compared with children of the same age, does (*NAME*) have difficulty remembering things? Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF19. Does (*NAME*) have difficulty concentrating on an activity that he/she enjoys doing? Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF20. Does (*NAME*) have difficulty accepting changes in his/her routine? Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF21. Compared with children of the same age, does (*NAME*) have difficulty controlling his/her behaviour? Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF22. Does (*NAME*) have difficulty making friends? Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty.....1 Some difficulty.....2 A lot of difficulty.....3 Cannot do at all.....4	
CF23. How often does (*NAME*) seem very anxious, nervous or worried? Would you say: daily, weekly, monthly, a few times a year or never?	Daily.....1 Weekly.....2 Monthly.....3 A few times a year.....4 Never.....5	
CF24. How often does (*NAME*) seem very sad or depressed? Would you say: daily, weekly, monthly, a few times a year or never?	Daily.....1 Weekly.....2 Monthly.....3 A few times a year.....4 Never.....5	

APPENDIX 2

DEVELOPMENTAL PROFILE TEMPLATE

Basic identifying particulars:
Name of child, age, ECD / pre-primary class, biographic details of parents and siblings

A semi-structured interview with the parents and/or caregivers can be conducted around the following topics:

- Parent's / caregiver's concern
- Mother's pregnancy and birth, breastfeeding
- Developmental milestones, including weaning, toilet training
- Health, including illnesses, conditions, hospitalisation and eating and sleeping habits / routines
- 'Traumatic' incidents – from a child's perspective, anything upsetting or frightening that happened to the child
- Relationship of child's parents, including, if applicable, dynamics related to separation and its effect on child
- Significant (moral and/or cultural) values in family system
- Child's attachment relationships, including other important caregivers in family system and siblings
- Educare / pre-primary / formal school attendance, including feedback given by educators on relevant developmental aspects
- Child's relationships in peer group
- Professional intervention, including recommendations given by service providers
- Support required for the child, from the parent's / caregiver's perspective.

APPENDIX 3

REFERRAL FORM

CONFIDENTIAL	
Service provider referred to	
Facility	
If applicable, date / time of appointment	
Child's name and surname	
Date of birth	
Age	
Parent / caregiver's name and surname	
Address	
Contact number	
Contact person (if not parent / caregiver)	
A developmental screening / assessment was conducted and significant issues regarding the following domains were found (mark which are applicable):	
☐ sensory and/or perceptual ☐ speech and/or language ☐ emotional ☐ physical ☐ behavioural	☐ motor ☐ cognitive ☐ social Other:_____
Details on reason for referral	
Signature of service provider referring	
Service provider name and surname	
Capacity	
Date	
Outcome of referral consultation	
Signature of service provider	
Service provider name and surname	
Date	
Please provide a copy of this form to the parent / caregiver and request her / him to attach it to the back cover page of the child's Health Passport.	

APPENDIX 4

DEVELOPMENTAL DISABILITIES AND ASSOCIATED MEMBERS OF MULTIDISCIPLINARY TEAMS

	Occupational therapist	Orthopaedic technician	Physiotherapist	Psychologist	Social worker	Speech-language therapist	SPECIALIST
Intellectual Disability (ID)	✔			✔	✔	✔	
Speech Sound Disorder					✔	✔	
Autism Spectrum (ASD)	✔			✔	✔	✔	Paediatrician Psychiatrist Paediatric Neurologist
Attentional conditions (ADHD)				✔	✔		Paediatrician
Specific Learning Disability (SLD)	✔			✔	✔	✔	Developmental optometrist
Cerebral Palsy (CP)	✔	✔	✔	✔	✔	✔	Orthopaedic surgeon
Epilepsy				✔	✔		Paediatrician Paediatric Neurologist
Foetal Alcohol Spectrum (FASD)	✔			✔	✔	✔	Paediatrician
Pediatric brain injury	✔			✔	✔	✔	Neuro-developmental specialist
Down Syndrome (DS)	✔			✔	✔	✔	Neuro-developmental specialist
Visual disabilities	✔			✔	✔		Ophthalmologist Optometrist
Hearing disabilities				✔	✔	✔	ENT specialist Audiologist Hearing acoustician
Albinism	✔			✔	✔		Dermatologist Ophthalmologist Optometrist

APPENDIX 5

GUIDELINES FOR THE EFFECTIVE USE OF THE HEALTH PASSPORT

1. The Health Passport is presented at every visit of the child to a service provider linked to her/his developmental needs, therefore also therapists. Its contents do not only provide developmental background information at a glance, but the record keeping layout also facilitates communication among professional stakeholders and, if applicable, coordinated service delivery by members of the multidisciplinary team.

2. The healthcare professional who issues the first Health Passport should ensure that the correct identifying particulars are entered. In the event of a birth naming ceremony that has to precede the entry of the name, the surname is entered and an arrangement made with the mother to return to a designated official for completion after the ceremony. Care must be taken that only one date of birth is used for the child, and that this date of birth is entered into the record.

3. Another Health Passport should only be issued if the healthcare professional is sure that the current record is filled, and no space is left for further notes. The simultaneous use of two records for one child should be avoided, on account of the confusion it will cause among service providers when two Passports are in circulation.

4. It is anticipated that the more complex the child's health condition and/or developmental needs are, the greater the number of Health Passports that will be issued during the course of the developmental years. Every new Health Passport should be given a serial number at the top of the page of the child's identifying particulars. With a view to information protection, parents should have the option that filled Health Passports are held in safe storage at a central facility, for example the regional developmental clinic. If this is the case, an inscription in the first line of the notes section of the new Health Passport will alert future professionals of where the previous Health Passport(s) is/are retained:

   "Health Passport (serial number of the full record) is held in safe keeping at (name of developmental clinic or office). For enquiries: (office phone number) and (e-mail address).

   Basic background information should be transferred from the most recent full record to the new Health Passport.

5. Entries should be made dutifully, in legible handwriting and with dates inserted. This will avoid inconveniencing and/or wasting the time of other professionals as well as incurring unnecessary expenses (Andrews et al 2006: 258). Details of very sensitive information are only recorded in the confidential patient / client file, and a note inserted in the Health Passport such as:

   "For further information, please consult the patient / client file at (name of facility) via (contact e-mail address)."

6. Although confidentiality of information entered in the Health Passport may be compromised due to wide circulation that inadvertently also gives access to other readers who are not regulated by a code of ethics, service providers are bound to honour the child's and her/his family's right to privacy. On the basis of their right to information, implications related to confidentiality and privacy should be discussed with the parents when the Health Passport is issued. Moreover, parents and caregivers are empowered as participants when time is taken to discuss professionals' notes on the child's development, identified disability and/or course of intervention.

7. When a child's development is significantly at risk or compromised, and her/his caregivers require additional support and assistance in this regard, a system to alert future professional stakeholders (for example, a colour coding system) can be put into operation. However, it is ethically required that the child's caregivers are informed of the system and its purpose is discussed.

8. It is advisable that a copy of the child's Health Passport is stored electronically, in the event of it getting lost or destroyed. A duplicate Health Passport can then be created.

CASE STUDIES

Various therapists and parents from Namibia contributed significant stories on different topics related to developmental delays and disabilities to be used for discussion during training. Names were changed to protect children's and their family's privacy.

1. Paulus

When Paulus's mother was expecting him, she was concerned. She requested a thorough check-up two weeks before his birth, but the prenatal nurse said, it was not necessary, everything would be fine. Paulus was in a bridged position at birth, and was born with hydrocephalus. When he was five days old, Paulus had to have an operation. Paulus's mother did not register the information about the operation shared with her by the nursing staff. In retrospect she recalled Paulus was prepared the night before, and she signed a document, but she was petrified the next day when she returned from the bathroom and her son was gone from the room and she learnt he had been taken to theatre. It felt like ages she was waiting, and at some point she was convinced he had died. Paulus had to have various operations as a baby. Paulus's mother found it hard to understand what his doctors were talking about – she did not understand the medical and disability terms they used. He developed paralysis and made use of a wheelchair.

For a long time after his birth, Paulus's mother asked herself, "what did I do wrong?" She never smoked or drank liquor. She did not know anything about disabilities as nobody in their families had a disability. According to the community, a child was either "normal" or "abnormal". Some community members believed their family were cursed, and therefore avoided contact with them in order to not bring the curse onto themselves. Their own family members no longer paid visits as they had done before.

For two years she went into hiding in their home. Then a CBR volunteer visited her. The first thing this volunteer told her was that she was not the only mother who had a child with a disability. A physiotherapist started to visit Paulus and his mother regularly. He had physiotherapy and massage, and the physiotherapist taught her how to position Paulus the correct way. The CBR volunteers drew her out of their home into the community. She started to have contact with other parents with children with disabilities, and since then she progressively supported more and more other parents of children with disabilities, first informally and later by setting up an organisation.

2. Case study of three-year-old Rosita

'I wanted to give my child up for adoption'

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OLIVIA Petrus contemplated giving up her child for adoption after her daughter was left disabled following an attack on her family last year.

Little Rosita* (3) lost her left leg and two of her fingers following the attack that left her grandmother and two other family members dead at their homestead at Epatululo village in the Okatope constituency, Ohangwena region.

On that fateful day on 6 November 2019, Rosita's uncle, Sem Nauyoma Petrus, allegedly chopped the three family members as well as two goats, to death with a panga.

Little Rosita miraculously survived the attack, but the incident left her mother traumatised. During an interview with *The Namibian* this week, an emotional Olivia Petrus (24) said she could not bear seeing her daughter without a leg and two fingers.

“I wanted to give her [Rosita] up for adoption. I did not know how I was going to look after her in this state,” she said. She added that since the incident, she has been crying herself to sleep, as she was not mentally prepared to care for a child with a

3. A six-year-old with Cerebral Palsy (CP)

The mother and her child of six years visited my practice. The child was only now diagnosed with CP by a private doctor. The mother on several occasions visited the state hospital in Town Z and every time the mother addressed the nurses and doctors about her child's development delay. The only answer she got was, the child will grow out of it and the mother shouldn't be so concerned.

4. Defying Expectations

A child who was not expected to walk, now cycles, walks, finished school and travels on his own.

5. Initially excluded

As a child, this young person was first excluded from school (and it was a fight to get her in). She finished her degree at University with cum laude and is a teacher herself now.

6. Early vs late identification of CP

Several cases of infants identified to have CP by paediatricians and referred for physiotherapy have received early interventions to prevent complications of immobility and also allow family education and referral for other modalities such as braces and wheelchairs. However, also several cases of children around 4/5 years old that have never been picked up as having these problems and by then the complications have become largely irreversible and can only be managed at that stage.

7. A 10-year-old child with CP

A child of 10 years with severe CP from Town Z was referred by a General Practitioner. The child was assessed and a Home programme compiled for his caregivers to use with him. They however did not follow through with OT even after several prompts and subsequently did not collect the Home programme. The child was never brought in again for intervention.

8. The one-year-old boy who had bilateral atresia

This case refers to a one-year-old boy who had bilateral atresia. (He had no ear canals.) The child was not conditionable, i.e., he could not hear the instruction and follow it. There was no specialised device (Auditory Brainstem Response with Bone Conductor) available. I could therefore not accurately measure how severe his hearing loss was and as such not fit him with the respective hearing aid. I could only "guestimate" based on what I thought would be an appropriate test to establish a possible level of hearing. I put the child in the sound proof booth sitting on his mother's lap and played various sounds through the speakers and watched as closely as possible to see if he would turn his head towards the sound - hoping that it will give me some indication. Based on the basics, he had a mild-moderate hearing loss

(35-40dBHL). As such I needed to try and get him a hearing aid that would suit that kind of loss - and more so, obtain the correct transducer (bone conductor) to help him to hear. About a year later, I managed to get the hearing aid (after having written a motivation letter for the procurement of hearing aids). I put the hearing aid on, but the child didn't want to wear it - it was too obvious (visible) and it seemed like it was uncomfortable. He kept on pulling off the device. I referred him to CLaSH to get support for the mother on how to better communicate with her son and how to try and let him use his residual hearing. Another year had passed and I finally received the specialised device to measure his hearing. His hearing loss was more of 25-35 dBHL (and classified as mild hearing loss). It's most likely the reason why he didn't want to wear his hearing aid - it was too loud for him. We reprogrammed the hearing aid and the next year he came back and the child was starting to talk a few more words than before. The child also seemed more determined to want to hear and listen, particularly when spoken to.

9. A one-year-old child with a history of severe jaundice

A mother brought her child to me recently. The child just turned one year old. The child had severe jaundice when it was born and now the child has developmental delays. The child was seen by a doctor at a state hospital and referred for Physiotherapy treatment in Windhoek, but never got an appointment. The child has still not received any therapy or any intervention or any further testing. The doctor said to the mother that the child would outgrow the problems it has, even though it is very obvious that the child has permanent brain damage as a result of the jaundice.

10. Hearing loss in young children

I see many children who first come for a hearing test at the age of three, four or five, because they do not speak yet. Then a major hearing loss is found, but then it is actually too late to have them develop normal speech and language by means of hearing aids / cochlear implants. If the same hearing loss was identified before / at one year of age, and effective intervention started, the child would have developed speech and language, would have attended a mainstream school and turned out to be an active member in her / his community. The parents of those few children who get identified early, often do not have the financial means to receive devices or implants, and subsequently "disappear" or get despondent.

11. The two-year-old with motor development delays

A mother brought her two-year-old who only sat and rolled. After six months' therapy, she walked.

12. Multidisciplinary intervention

Motivated parents came in with their son, about four years old, who was not speaking and seemed developmentally delayed. Along with a questionnaire, and some unstructured play, a functional assessment was done which indicated that his receptive language was far better than his expressive language and he did not seem to be intellectually challenged. The parents

were referred to the team of other specialists involved in the diagnosis. The parents got ideas and tips on how to manage the challenging behaviour, how to communicate with a symbol communication board and how to use schedules and plans to provide structure and routine. Later the child attended mainstream school.

13. The three-year-old with profound hearing loss

A three-year-old child with profound hearing loss was referred to CLaSH by the speech therapist from Windhoek Central Hospital. The CLaSH team organised a home visit to the family. The process of applying for the special maintenance grant, the possibility and processes involved of getting a hearing aid, and the various educational options were explained. The family managed to find accommodation for the young child with family members in Windhoek and the child started attending the CLaSH Pre-School and Day-Care Unit. She was fitted with hearing aids, learnt Namibian Sign Language and received holistic stimulation through the combination of Montessori and Early Deaf Education approach that the CLaSH Unit follows. When the child turned six, i.e., after two to three years of focussed early intervention, the parents were assisted to apply for admission to one of the Government Schools for the Deaf. A well-prepared and school-ready child entered the formal education system.

14. A five-year-old girl with challenging behaviours

A single mother came with a girl-child of the age of five. The child spoke well above her age, but is expelled from day care after day care due to aggression and non-compliance. The family rejected the mother and child, because of the girl's challenging behaviour. Their town does not have a hospital or any therapist. Our organisation did not have sufficient funds to assist adequately by providing resources, but the mother joined a whatsapp group where other parents also gave tips and ideas on how they coped with such behaviour.

15. A six-year-old child who was deaf

A child of six years old, had been deaf and did not speak since birth. The clinic nearby had nothing to offer and the mother saved up some money to take her child to the regional hospital. There she was told they did not have an audiologist and all their machines were broken anyway. She was referred to Windhoek, but while she could not afford the trip she requested to be put on the list for the ambulance. The date was given for several weeks later, but when she arrived at the regional hospital, the ambulance was filled with "more critical" cases. This happened two more times over a period of several months and the mother gave up.

16. Abed's education

Abed was turned away for school enrolment, because of a speculation that he had a learning disability and other developmental delays. His parent took him to a centre where he was taught basic Sign Language.

17. Angel's story

Angel's mother was on drugs and abused alcohol while pregnant. After the birth, the doctor told the mother that Angel will not be able to see, speak or walk. When she was 11 months, her mother and maternal aunt took her to the witch doctor who gave her medicine. After she was given the medicine, Angel had to be admitted to hospital and she nearly died. She was placed in foster care and referred to a developmental clinic. She started to walk when she was five years, and at the age of 10 she started to say words. She developed a limited vocabulary and mostly communicated non-verbally. At the age of 18 she no longer wore a nappy at night. She was able to use the toilet independently, but her foster mother still packed spare clothes in her day care bag. Angel had strabismus and wore spectacles. Moderate ID was found when she was assessed.

18. The impact of iron on Dingha's development

Dingha was born full-term. He was breastfed for three years and his motor development was according to expectations. At the age of one he got hold of his aunt's "pregnancy pills" – her iron supplement – and ate some. He became weak while he played and his mother took him to hospital. "The doctor said, his brain was touched by the iron." At the age of six he developed seizures. Dingha was unable to learn to read and write, while he attended school from eight to 15 years. Then he joined an APD group for young adults. When he was assessed, severe ID was identified.

19. Six-year-old Jabu

Jabu is six years old. He is incontinent and wears a nappy. Although he needs someone to change him, his mother has no choice but to leave Jabu at home when she goes to work. She is a single parent and cannot afford to pay for a caregiver.

20. Betsy and the ECD centre

Betsy is 32 months of age. She does not speak yet but sings along when "baby songs" are sung to her, and Betsy does not feed herself yet. She gets upset easily and usually responds with aggression if she is unhappy with something. Betsy has little interest in interacting with others; she prefers to be on her own. If her parents want to keep the peace among the siblings, it is best to just leave her to be on her own. She also does not show interest when a parent or sibling shows her something. At the ECD centre, she just ignored her educarer or anyone encouraging her to participate in a group. It was reported that she is very active and on the move all the time. Betsy only wanted to be outside. The centre requested the parents to find another school for Betsy as they are not equipped and trained to accommodate her. Betsy's parents feel overwhelmed. They need guidance to help their child. They want her to be comfortable among other children.

21. Waldo presents with developmental delays

In retrospect Waldo's parents realise that they were in denial of the delayed development of their son. Most obvious was how late he started to speak. He is in his own world, although he enjoys to do his school work with the support of the class assistant. He likes Maths, but finds English very challenging.

22. Bobby and the sensory room

Since Bobby has been given ample time in the sensory room of his new school, he no longer bites other children and is more cooperative when it comes to structured activities. His teachers have found that he can have longer conversations with them while he sits in the "tent".

23. Maku enters school

It took the principal of Maku's new school at least one week to get Maku to enter the school building. The next step was to get her into her classroom. Maku was also very anxious when she had to use the toilet at first, but now it is fine.

24. Capo has hemiplegia

Capo has hemiplegia that affects the right side of her body. She has to repeat Grade 1 in the learning support class this year, because of poor handwriting.

25. Ruwaan is accepted

TB was diagnosed one month after Ruwaan was delivered by C-section. He ran a very high fever and a shunt was inserted for hydrocephalus. Ruwaan developed epilepsy. He stayed in hospital for 10 weeks. At first his mother rationalised that nothing was wrong, but after the many tests she became anxious about where she would get the financial means as a single parent to afford her son's medical expenses. The question of what she had done to deserve a baby with a severe disability, haunted her for a period of time. But then Ruwaan's mother realised that she was not the only parent who had a child with a disability. The support she had received from her family – and particularly Ruwaan's grandparents – helped her to accept his disability.

26. Baby Josephine

During the birth of Josephine, her mother sensed that the maternity staff was discussing some issue with one another without telling her about it. When she arrived home, she observed Josephine's arm stayed either behind her head or on top of it. When Josephine was taken for immunization at a later stage, her mother was told that she had a physical disability. Only her motor developmental track remained behind the expected ages.

27. Pumi's "diagnosis"

At the age of three years, Pumi was very active and a CT brain scan was done. The doctor told her mother Pumi had "brain cancer".

28. The story of Daniel

The three-year-old Daniel was a very active toddler. He fell head first into a pool of water and choked. Daniel contracted poliomyelitis. He was in and out the hospital, and had to have operations. Only at the age of seven, it was explained to them that this was the physical disability was as a result of the polio.

29. Kuthi is physically abused

When Kuthi was three months old, she was placed with a foster parent. At the age of seven years, Kuthi ran away due the physical abuse she endured over the years. She stayed in hospital for eight months. She still has difficulty walking.

30. Luna's beliefs

Luna links the epilepsy she has to witchcraft. She believes that someone was jealous of her and put a spell on a pen that Luna had used at school. After the diagnosis, she did not return to school. According to her, the doctor instructed her not to go back.

31. Benjamin

Benjamin developed paralysis of the legs after he turned three. He stayed in hospital for 18 months. Due to a spinal cord injury his mobility progressively deteriorated to the point that he started to use a wheelchair. He went to school from Grade 1 to Grade 3. He did not return to school after a long absence in Grade 3 when he another operation.

32. What caused Mina's hearing loss?

Mina's mother got very angry with her. By using both hands, her mother hit Mina's ears simultaneously very hard. She developed hearing loss in both ears.

33. Albino pupils looking for help

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by Taati Niilenge

THREE albino boys from the !Nara Primary School at Walvis Bay are appealing to Good Samaritans to help them cope with their condition.

The boys, aged 8, 10 and 12 say it is difficult for them to focus in school since their eyesight

is very weak. According to one of their teachers, Lucinda Resandt, the boys have been performing very poorly as they have difficulties reading, especially on white paper. "We also tried to move them to the front of the class in order to focus better, but it is not helping much," she said.

Resandt said their eyes are mostly affected when they need to move around between classes, during break time, and when they have to walk the long distances to school and back home. Because of this condition, they usually just sit somewhere in the shade when others are playing in the sun. We do not have much knowledge on how to search for help, but we hope some people will come forward and offer the necessary help. The children's parents cannot afford much, so we decided to ask for help from the public," she said.

Frans Shikalepo said he struggles in the sun. "My skin bursts when I walk in the sun. I want some help to make it stop. I also need some glasses so that I can read well, and my eyes need protection," said Shikalepo.

34. A father's dream for his sons

YOKANY OLIVEIRA

Sheiddy Nsamba, a nine-year-old boy with disability, demonstrates how he uses his mouth to draw a sports car (inset). He was diagnosed with pseudo-arthrosis at birth, a condition formed by fibrous tissue between parts of a bone that have fractured, usually spontaneously, due to a congenital weakness. He cannot walk or use his arms or hands, instead he uses his mouth to hold the pen and executes the drawing.

Julius Nsamba carries his curriculum vitae and other documents with him on a regular basis. The optimistic 31-year-old is always smiling, but today he seems a bit nervous as he is inviting a stranger into his Okahandja Park home, just outside Windhoek, for the first time.

The Namibian spent some time with Nsamba and his family in their corrugated zinc shack.

Nsamba, who is unemployed, spends most of his days looking for odd jobs around the city to supplement the N$500 per month the family receives in social grants.

His partner, Rayava Cecilia (27), is left at home to look after their three boys: Izecky (3), Siwogedi (7) and his eldest, Sheiddy (9), who is living with a disability called pseudoarthrosis. According to the Merriam Webster medical dictionary, pseudoarthrosis is an abnormal union formed by fibrous tissue between parts of a bone that have fractured, usually spontaneously, due to a congenital weakness – also called a false joint.

Sheiddy was born in 2010. His medical examination certificate states that his condition, which is a result of a congenital defect, is permanent and will worsen over time.

In 2009, before Sheiddy was born, the couple, like many villagers seeking greener pastures, moved to the city for what they hoped would be a better life, but.

"I am not so sure if she is home," he says of his partner, as his seemingly optimistic smile fades. Nsamba says Cecilia was out early to catch bright green mopane worms alongside the B1 road. This is what the family would consider a meal on most days. Other times, she makes relish and sells it around the informal settlement for money to buy more food.

When the parents go out to work, big brother Sheiddy is left with his seven-year-old brother, while energetic Izecky accompanies his mother to catch the worms.

Carefully leading the way, Nsamba cautions us to watch our step as we walk through the gravel streets of the informal settlement where most of the shacks are situated on the hilly terrain.

He carries Sheiddy around with difficulty because of his fragile condition.

Occasionally, the family will attend a church service in Katutura, but the journey, often long and costly, requires both him and Rayava to push their disabled son around in a wheelchair.

Dusty toys lie scattered between sand and stones around the entrance of the yard, many of which are old rundown sports cars, a clear indication that this is the boy's play centre.

The shack sits near the bottom end of a steep, rocky hill.

When we arrive inside the family's home, the boys, Sheiddy and his youngest brother Izecky, are sitting quietly next to the door, waiting for the guests to arrive.

Siwogedi is outside playing with his friends. Big brother Sheiddy calls out his name and he arrives.

Sheiddy's disability, though, has left his limbs disfigured.

His legs are crossed and his small hands bent, with huge calluses on the top of his wrists. Even though Sheiddy is also able to play, he has limitations.

Usually, he plays indoors where there is a rug protecting his thin skin from bruises or in outside areas with soft sand and small stones, or by the smooth gravel road, supervised by his parents and brothers.

Although the nine-year-old is unable to walk, we observe his cognitive functions are fully intact, and he is able to express himself in his mother tongue Rukwagali, with some understanding of very basic English. He exhibits good comprehension skills when spoken to.

His crossed legs have sustained bloody and open bruises from the stones.

But Sheiddy is full of life, despite his condition.

“We use a wheelchair when going to church or when we accompany him to the playground,” Nsamba explains.

There is a double bed base with no mattress in a small room on which Rayava, Nsamba and Izecky sleep. Sheiddy and Siwogedi sleep on the floor on a small mattress.

The family’s shack which does not have a cement floor has a large rug covering the floor to protect their feet and Sheiddy’s fragile limbs from the small stones underneath. They did not have a rug at their previous shack and this resulted in Sheiddy sustain-ing bruises from the rough stones as he moved around.

“During the day he cannot go outside until the sun sets, and then there is some shade

to protect him as he plays with the other children,” Nsamba added.

Rayava displays a visibly shy disposition as she sits next to Nsamba. She needs him to translate into English her daily struggles as a mother.

“I don’t see most of my friends, because I am always looking after the boy. I cannot be free,” she explains in Rukwangali.

“Sometimes, the boys around here are very naughty. They call him [Sheiddy] bad names,” Nsamba says, adding that his mother usually watches over him while he plays outside.

It is for this reason that Sheiddy prefers to play with his brothers most of the time.

SOCIAL STIGMA
Last year alone, the family moved houses several times in this location as they could not afford a steady rent.

There are a few people in the community who have ostracised the family, and whenever Sheiddy is bullied, he often comes home crying.

Nsamba shows us a book by an Australian motivational speaker, Nick Vujicic, a man who was born without arms and legs.

“I tell my son: ‘You are better, look at this man with no arms or legs, he is happy and laughing’,” he says.

Celicia and Nsamba say a pregnant woman refused to walk near their yard, because she believed that her baby would be born with a disability like Sheiddy.

“As his father, I try to encourage him,” he says. “To make him feel happy.”

A GIFTED CHILD
Nsamba explains his sons have never received a formal education.

Sheiddy, however, attended school sporadically in Khomasdal and Katutura, but after his father lost his job as a security guard last year, he has not been able to pay for his children's education.

Despite his lack of education, Sheiddy has remarkable drawing skills. We asked him to draw something with a pen on a piece of paper.

Because his hands are severely affected by the pseudoarthrosis, his father puts one end of the pen in his mouth. Remarkably, he bends towards the paper and draws a big car on a road, perfectly, holding the pen between his lips.

"I want to go to school again," Sheiddy tells this reporter.

Nsambo told The Namibian that he plans on taking Sheiddy to a nearby kindergarten, as **they offered to take care of him in the meantime until Nsamba is able to secure a place for him in a special school.**

MEDICAL CARE
Nsamba has been advised by concerned members of the public to take Sheiddy to the Windhoek Central Hospital's children's ward for treatment of malnutrition.

He is, however, still preoccupied with searching for odd jobs around Windhoek to support his family and provide his sons with adequate medical care.

END NOTES

[1]"(T)he developmental-versus-difference controversy is this: Do all children – regardless of intellectual impairments – progress through the same developmental milestones in a similar sequence, but at different rates? Or does the development of children with mental retardation proceed in a different, less sequential, and less organized fashion?" (Mash & Wolfe 2010: 280).

[2]Quantitative refers to descriptions by means of numerical values and operations, and qualitative refers to non-numerical descriptions.

[3]For example, a norm group of four-year-olds will be used for comparison, when a six-year-old attains an age equivalent of 04 years 05 months for some aspect of language development.

[4]A temper tantrum has a purpose in mind – getting something she/he wants or getting out of something she/he does not like.

[5]"The process, usually caused by excessive sensory stimulation, of becoming 'undone' or 'unglued,' accompanied by screaming, writhing, and deep sobbing" (Kranowitz 2005: 313).

[6]Meningitis is a neurodevelopmental condition caused by inflammation of the membranes that encapsulate the brain.

[7]"A percentile score is the percentage of people in a normative standardization sample who fall below a given raw score" (Roodt 2009: 39).

[8]Early infantile autism, Kanner's autism, atypical autism, high-functioning autism, Asperger syndrome and Pervasive Developmental Disorder (PDD), as well as Pathological Demand Avoidance Syndrome (PDA) that belongs to the PDD "family" (PDA Society 2016: 11)

[9]craving and eating unusual substances

[10]Intersubjectivity is "the appreciation and sharing of the subjective state of another individual" (Stefanos & Baron 2011: 255).

[11]Expressive language refers to production of language and receptive language to its comprehension.

[12]structured according to the rules of syntax and semantics

[13]"Pronoun reversals occur when the child repeats personal pronouns exactly as heard, without changing them to suit the situation. For example, a child named Tim when asked, 'What's your name?' answered, 'Your name is Tim," rather than 'My name is Tim'" (Mash & Wolfe 2010: 307). Pronoun reversals indicate a problem with deixis, which is the language code "shifting reference between the speaker and the listener" (Gerenser & Forman 2009: 571). To become confused with "this" and "that" is also part of deictic difficulties.

[14]"Echolalia can either be immediate or delayed and is the child's parrot-like repetition of words or word combinations that she or he has heard" (Mash & Wolfe 2010: 307).

[15]Perseverative speech is "incessant talking about one topic and incessant questioning" (Mash & Wolfe 2010: 307).

[16]using an existing word in an unusual context or creating a new word

[17] describing something by means of (often an unusual) personal comparison, e.g., "'ice cream trees' to refer to snow-covered trees" (Prelock & Nelson 2012: 130)

[18] Instead of analytical processing, the child employs gestalt processing. Consequently a phrase is used to denote a single word: "'timetotakeabath' (means) 'bath'" (Stiegler 2015: 751).

[19]using dialogue from stories, movies etc. during interactive play

[20]Examples are body rocking, hand flapping, staring at lights or propelling objects, or smelling things.

[21]"Study" of dinosaurs or sharks for example, including knowledge of biological taxonomy

[22]Detailed pictures drawn with a black fine liner by a five-year-old

[23]Nonverbal ASD refers to children with ASD who do not develop skills for verbal communication and therefore do not speak.

[24] DSM-5: Attention Deficit / Hyperactivity Disorder

[25]DSM-5: Specific Learning Disorder

[26]stiff muscle tone

[27]floppy muscle tone

[28] oxygen deprivation during the birth process long enough that the newborn incurs physical harm (usually to the brain)

[29]neonate with central nervous system (CNS) dysfunction caused by some agent or condition

[30]neonate with central nervous system (CNS) dysfunction caused by some agent or condition

[31]before 2 years, between 2 and 4 years, between 4 and 6 years, between 6 and 12 years, and between 12 and 18 years

[32] "Aspiration occurs when there is interference in the synchronization of the swallowing / breathing process. Aspiration is defined when food passes through the larynx vestibule, passing below the vocal folds into the trachea and lungs" (Araújo et al 2012).

[33]"Gastrointestinal (GI) motility refers to the movement of food from the mouth through the pharynx (throat), esophagus, stomach, small and large intestines and out of the body. The GI system is responsible for digestion." https://health.ucsd.edu/specialties/gastro/areas-expertise/motility-physiology/pages/default.aspx

[34] Dysphagia is a swallowing disorder that makes the transportation of bolus from the mouth to the stomach difficult (Araújo et al 2012).

[35]Also known as infantile regurgitation, gastrointestinal reflux refers to the involuntary flow of gastric contents back into the oesophagus (ibid).

[36]"In medicine, gastric emptying is … a natural process consisting of ejecting the stomach's contents [into the small intestine]. When the body is functioning normally, this occurs a few hours after eating. It can, nevertheless, be delayed or accelerated by certain conditions, such as diabetes, gastric ulcers, or neurological disorders." https://health.ccm.net/faq/3009-gastric-emptying-definition [addition for clarity]

[37] Constipation is the passing of hard and large stools while experiencing pain or discomfort during bowel movement that is limited to a frequency of less than three times a week.

[38] forces affect brain tissue at the point of impact

[39]forces affect brain tissue at the opposite pole to impact

[40] Astrocytomas are … classified for presenting signs, symptoms, treatment, and prognosis, based on the location of the tumor. The most common location of these tumors is in the cerebellum where they are called cerebellar astrocytomas. These tumors usually cause symptoms of increased intracranial pressure, headache, and vomiting. There can also be problems with walking and coordination, as well as double vision. https://www.stanfordchildrens.org/en/topic/default?id=childhood-cerebellar-astrocytoma-treatment-pdq-37-CDR0000062783

[41]"Early onset hydrocephalus occurs in children within the first year of life as a result of congenital or perinatal disorders. The increased cranial pressure in the brain can cause increased head size and lasting damage to the brain tissue as it gets compressed and squeezed against the skull. A common treatment for children with hydrocephalus is to surgically implant a shunt to drain the extra cerebralspinal fluid into the abdominal cavity. Children with early onset hydrocephalus have been found to have deficits in both fine and gross motor coordination, visual-motor and visual-spatial processes, some language delays, problem-solving skills, and focused attention" (Miller 2007: 73).

[42]formation of connections among nerve cells

[43]Word deafness refers to words that cannot be understood.

[44] Basic auditory information processing is intact, but the child cannot link the sensory information (sounds) to meaning. This difficulty is not attributed to cognitive dysfunction (Banich & Compton 2011: 202).

[45]"tonic" refers to muscle stiffening and "clonic" refers to the jerking of muscles

[46]DSM-5: Foetal Alcohol Spectrum Disorder

[47]rules pertaining to syntax and semantics

[48]"Successive processes provide the integration of stimuli into a serial order in which the elements form a chainlike progression. The distinguishing quality of successive processing is that each stimulus is related only linearly and that each stimulus is related only to the one it follows" (Das & Naglieri 1996: 121)

[49]This is complimentary to the definition of intelligence by Das and Naglieri (para 4.1).

[50]A behavioural phenotype is defined as "the heightened probability or likelihood that people with a given syndrome will exhibit certain behavioral and developmental sequelae relative to those without the syndrome" (Hodapp & Dykens 2009: 116).

[51]"Simultaneous processes allow the individual to integrate stimuli into groups in which each component of the stimulus array must be interrelated to every other. Simultaneous processing may take place when stimuli are perceived (e.g. when a child copies a design such as a cube), remembered (e.g. when the design is drawn from memory), or conceptualized (e.g., when the child reasons about a design …). Simultaneously processed information is said to be surveyable because the elements are interrelated and accessible to inspection either through examination of the actual stimuli during the activity (as in the case of design copying) or through memory of the stimuli (as in the case of reproduction of a design from memory)" (Das & Naglieri 1996: 120-121).

[52]rapid involuntary eye movement

[53]direction of eye(s) either inward or outward

[54]reasoning independent of receptive / expressive language abilities

[55]With a cochlear implant, "an internal electromagnetic coil, with an electrode that runs into the cochlea of the inner ear, is placed in the mastoid bone behind the ear. An external coil is fitted on the skin right over the internal coil. Sounds are picked up by a microphone worn on the clothing and are sent on to the cochlear nerve in the inner ear by way of the external coil, internal coil, and the electrode in the inner ear" (Hallahan & Kaufman 1988: 270).

[56]sensitivity to light

[57]nearsightedness (myopia), farsightedness (hyperopia) and astigmatism (blurred sight) (Landsberg 2011: 367)

[58]Macronutrients refer to classes of foods that provide energy to the body, i.e., carbohydrates, fats and proteins.

[59]Promoting healthy development
https://brightfutures.aap.org/Bright%20Futures%20Documents/BF4_HealthyDevelopment.pdf

[60]"A norm is a measurement against which an individual's raw score is evaluated so that the individual's position relative to that of the normative sample can be determined" (Roodt 2009a: 38).

[61]UNICEF, https://youtu.be/lj6iqkaSCGQ

[62]"The reliability of a measure refers to the consistency with which it measures whatever it measures" (Roodt 2009b: 47).

[63]"The validity of a measure concerns what it measures and how well it does so" (Roodt 2009c: 56).

Republic of Namibia

Namibia Statistics Agency