



THEORY OF CHANGE



Early Identification and Early Intervention Services
for Young Children with
Developmental Delays and Disabilities in Namibia
Regional Consultations Report



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for Young Children (0 to 6 years) with
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ACKNOWLEDGEMENTS

The regional consultations on the early identification, assessment and referral to services for children with disabilities was conducted within the framework of the project on Strengthening Integrated Systems to Promote Access to Services for Persons with Disabilities in Namibia. The project is jointly being implemented by UNDP, UNFPA and UNICEF and supported by the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD), under the coordination of the Office of the President: Disability Affairs.

A word of thanks and appreciation goes to Dr Hetta van Niekerk for conducting national and regional consultations with over 200 stakeholders and compiling this invaluable report which highlights challenges faced by children with disabilities in Namibia before formal education.

Conducting the extensive review required considerable inputs from a wide range of stakeholders, including parents, Ministries of Health and Social Services, Education, Arts and Culture, Gender Equality, Poverty Eradication and Social Welfare, Office of the President: Disability Affairs, the University of Namibia, organizations working with persons with disabilities and disability service providers, teachers, health experts from both the private and public sectors, as well as UNICEF Headquarters and the UNICEF Regional Office for Eastern and Southern Africa. We would like to thank all the stakeholders who played a crucial role in providing information and sharing their views and perceptions on the services provided to children with disabilities, which informed the development of training modules on the subject matter.

Special thanks go to the UNPRPD for providing financial support to Namibia to implement the project which is aimed at strengthening the voices of persons with disabilities.

Cover Image: Teacher with pre-primary learners at the Association for Children with Language, Speech and Hearing Impairments of Namibia (CLaSH)

Pages 10-15: Regional Maps of Namibia (Jo Rogge)

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LIST OF ABBREVIATIONS AND ACRONYMS

| | |
|--------|--|
| AAC | Alternative and Augmentative Communication |
| ADHD | Attention Deficit / Hyperactivity Disorder |
| ASD | Autism Spectrum Disorder |
| CBR | Community-Based Rehabilitation |
| CP | Cerebral Palsy |
| CRPD | Convention on the Rights of Persons with Disabilities |
| CwD | Child with a Disability |
| DATS | Diagnostic and Training Services |
| DSM-5 | Diagnostic and Statistical Manual of Mental Disorders, fifth edition |
| ECD | Early Childhood Development |
| ENT | Ear, Nose and Throat |
| ICD-10 | International Classification of Diseases, 10th revision |
| ICF | International Classification of Functioning, Disability and Health |
| ICF-CY | International Classification of Functioning, Disability and Health, Children and Youth version |
| ID | Intellectual Disability |
| EIEI | Early Identification and Early Intervention |
| ILSP | Individual Learning Support Plan |
| FAS | Foetal Alcohol Syndrome |
| LD | Learning Disability |
| MGECW | Ministry of Gender Equality and Child Welfare |
| MHAI | Ministry of Home Affairs and Immigration |
| MoEAC | Ministry of Education, Arts and Culture |
| MoHSS | Ministry of Health and Social Services |
| MoSY | Ministry of Sport and Youth |
| MoU | Memorandum of Understanding |
| MPESW | Ministry of Poverty Eradication and Social Welfare |
| NIED | National Institute for Educational Development |
| OT | Occupational Therapist |
| OVP-DA | Office of the Vice President, Disability Affairs |
| PT | Physiotherapist |
| PwD | Person with a Disability |
| SLD | Specific Learning Disorder |
| SLT | Speech Language Therapist |
| SW | Social Worker |
| TBI | Traumatic Brain Injury |
| UNCRC | United Nations Convention on the Rights of the Child |

Since independence in 1990, the Namibian Government has committed to address inequalities faced by the population and to ensure the protection of its citizens through the provisions in the Namibian Constitution. The 1990 Namibian Constitution explicitly recognizes the inalienable human rights and freedoms of all its citizens. In addition, Namibia set national development priorities that impact the well-being of the nation through Vision 2030 and the National Development Plans. These national priorities are also in line with the international instruments and Global Agenda for Sustainable Development 2030 and the Sustainable Development Goals (SDGs). As a country, Namibia has been addressing the rights of person with disabilities through the ratification and implementation of global, regional and of national instruments.

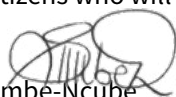
In line with its constitutional obligations and arguably as a sign of goodwill the Namibian Government ratified the Convention on the Rights of Persons with Disabilities (CRPD) and the Optional Protocol on 4 December 2007. Equally, Namibia has ratified, the Convention on the Rights of the Child (CRC) of 1989, the African Charter on the Rights and Welfare of the Child (ACRWC) of 1990, and have signed, in support of the goals enunciated therein, the Sustainable Development Goals and Agenda 2063 of the AU. At the national level, the National Policy on Disability was launched in 1997 and the National Disability Council came into force after the enactment of the National Disability Council Act (Act No. 26 of 2004) in 2004. As recent at 2013, with the support of UNICEF, the Sector Policy on Inclusive Education was launched in 2013.

According to the national data, 26,992 children under 18 have a disability, and 5,529 of these children are receiving a disability grant. According to the Namibia Inter-Censal Demographic Survey Report (2016), 52.2 % of persons aged 4 years and above had difficulties in engaging in any learning activity. The majority of these are found in rural areas. The National Housing and Population Census of 2011 revealed that 87% of children with disabilities between the ages of 0-4 years have never attended early childhood development (ECD) programmes while the proportion of persons with disabilities aged 5 years and above that never attended school was higher in rural (82.1%) than in urban areas (17.9%).

In support of these SDGs, Namibia has a conducive legislative and policy environment, addressing the needs of vulnerable communities and persons with disabilities. However, a gap still remains between policy and implementation, primarily because of lack of standards, competencies to identify developmental delays and difficulties during their early years to provide them with early intervention skills, including public awareness and understanding. Lack of adequate services has also led to stigma and discrimination, limited access to early learning and protection, education, health care, employment opportunities and resources. However, there are several parents' associations advocating for improved access of children with disabilities to quality early intervention services, health, education and social services.

It is evident that if children with disabilities receive good care and developmental support in early childhood, and are recognized as fully-fledged members of society, they will become healthier, more productive and valued members of their society. This would clearly lead to a return on investment in terms of future state expenditures on health care, rehabilitation, and social benefits, as well as reduce the dependency of persons with disabilities on charity support. This will offer them a better standard of life with dignity where their rights are respected and protected.

I therefore call on all stakeholders, public and private, to support efforts towards the early identification of all children with disabilities and to refer them for early assessment so that they can receive the necessary support services, without any stigma and discrimination, to allow them to survive and thrive into healthy responsible Namibian citizens who will equally contribute to the economic and social development of our country.



Alexia Manombe-Ncube
Deputy Minister for Disability Affairs

Being signatory to international instruments, including Agenda 2030, Namibia has committed to attaining the Sustainable Development Goals (SDGs) by the year 2030. Early childhood development in Goal 4 of the SDGs is to : *“Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all.”* Target 4.2 of the SDGs 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.”* Providing services early helps children catch up and increase their chances for success in school and life overall.

Evidence-based interventions in early life can mitigate disabilities and developmental delays. Early interventions in ECD set a path for good lifelong health with lower incidences of non-communicable diseases. Therefore, parents and guardians should be provided with adequate support as early as possible through early identification and targeted family support interventions. One of the barriers to timely provision of appropriate continued services for children with identified developmental delays and difficulties is the absence of a clear referral systems and capacities of parents, guardians or services providers. The fragmentation of services and lack of coordination also results in a missed opportunity to support children more effectively.

Through the implementation of the UNPRPD funded project on Strengthening Integrated Systems to Promote Access to Services for Persons with Disabilities in Namibia, UNICEF is providing technical assistance to strengthen and promote services for the early identification and early intervention of services at an early stage to enhance opportunities for maximum participation in inclusive settings. Programmes for early identification, assessment and intervention should bring together the right combination of interventions that can be implemented through existing systems at all levels - national, regional and community levels. When developing such programmes, it is recommended to conduct analyses of existing services for packaging of interventions based on family and child needs. This may include the basic health services, social support, protection and support in child development and education.

Through the project on Strengthening Integrated Systems to Promote Access to Services for Persons with Disabilities, UN Agencies will focus on advocating for the full and effective participation and inclusion of persons with disabilities in Namibian society. The UN remains committed to supporting the government, in particular, the Office of the President: Disability Affairs to advocate for access to all services for children with disabilities and to ensure that ‘no one is left behind.’



Rachel Odede
UNICEF Representative

Eight research questions were formulated in accordance with the Terms of Reference of the consultancy project (Inception Report). A review of documents and manuals pertaining to early identification and intervention services to children 0 - 6 years with developmental delays and disabilities was conducted (Comprehensive Report). With the aim of developing a theory of change to improve service provision and related training, an analysis of the current identification and intervention system (EIEI) in Namibia was conducted.

This report is organised into four sections. The three cycles of information analysis pertaining to the current EIEI system in Namibia are covered in Sections 1 - 3:

- Section 1: Stakeholder interviews and consultations during the mission to Namibia from 22 - 24 October 2019;
- Section 2: Fieldwork in Namibia during January and February 2020; and
- Section 3: Responses to the electronic questionnaires from educational institutions, support groups/ disability organisations and professionals.

From these themes the theory of change evolved, aiming to improve the quality of services to children with developmental delays/disabilities in the age group 0 - 6 years. The proposed theory of change is discussed in Section 4.



Homemade therapeutic hang-mat for children with disabilities

SECTION 1

1. STAKEHOLDER VIEWS ON CURRENT EIEI SYSTEM

A mission to Namibia was undertaken from 22 to 24 November 2019. During meetings with the different stakeholders (inception report), informative perspectives relating to strengths, barriers and gaps of the current system were offered. The themes that emerged are summarised in the following paragraphs.

1.1 Strengths

- 1.1.1 A system to identify and assess learners with specialised needs is operational at the Diagnostic Assessment and Training Services (DATS) division of the MoEAC.
- 1.1.2 Collaboration between parents and service providers has shown to add value to the system.
- 1.1.3 Some referral systems are functional.
- 1.1.4 Existing tertiary education curricula can be adapted to include course work on early identification of developmental challenges and its intervention.

1.2 Barriers

- 1.2.1 The quality of service provision is below standard.
- 1.2.2 Dissemination and utilisation of existing educational information is inadequate.
- 1.2.3 Service providers do not follow prescribed procedures and protocols. Specific issues include utilising the Health Passport and screening for hearing loss.
- 1.2.4 There is a lack of clarity concerning division of roles and/or functions among role players in the public sector.
- 1.2.5 Impractical policies hinder quality of service.
- 1.2.6 There is a lack of accountability for the care and maintenance of specialist equipment.
- 1.2.7 The rendering of intervention services is directly related to the provision and/or availability of specialist staff within the system.
- 1.2.8 It is difficult, if not impossible, for parents and/or caregivers to access services for their children.
- 1.2.9 Inclusive learning environments are not equipped according to the educational needs of children with developmental delays and disabilities.

1.3 Gaps

- 1.3.1 ECD is not recognised as the foundation to all education.
- 1.3.2 Parents and/or caregivers are unaware of the importance of monitoring developmental risks and early intervention.
- 1.3.3 Information is needed to empower parents and/or caregivers.
- 1.3.4 Service providers do not have adequate knowledge of, or training in procedures.
- 1.3.5 Some primary health care activities require (additional) procedural guidelines with regard to screening, referral, monitoring and case management.
- 1.3.6 A culture of professional collaboration and multi-disciplinary team work is not well established among role players.
- 1.3.7 Developmental assessments are not routinely conducted.
- 1.3.8 There are limited or no services for intervention.
- 1.3.9 Not all regions have ECD centres equipped to accommodate pre-schoolers with specialised educational needs.
- 1.3.10 A policy framework to inform decisions regarding inter-sectoral collaboration is required.
- 1.3.11 Additional modules are required for training at a tertiary level.

The research activities during January – February 2020 comprised of semi-structured focus groups or interviews, visits and observations at facilities (Appendix 1), and involved 211 participants at the regional fieldwork sites in Namibia. The demographics of the participants are reflected in Appendix 2. Relevant information pertaining to early identification and intervention emerged from this research, and is presented in this section.

2. FACILITIES

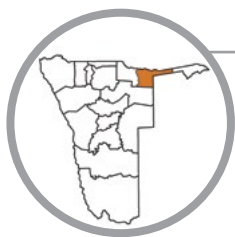
2.1 Residential facilities for children with disabilities

2.1.1 Cheshire Home, Katima Mulilo



Cheshire Home accommodates between 20 and 30 children with disabilities from the northern regions of Namibia. The children have access to physiotherapy at the home, and in collaboration with the local clinic, mobility equipment and other devices are procured. The children are also referred to MoHSS for social services, e.g. counselling, birth registration and disability grant application. The children attend inclusive schools in the area.

2.1.2 Dr Romanus Kampungu Secondary School Hostel, Rundu



The hostel on the premises of Dr Romanus Kampungu accommodates a total of 500 learners from Grade 1 to Grade 12. Approximately 80 boarders attend the Special Unit (Grade 1 to Grade 7) for Visual Impairment and Learning Difficulties adjacent to the secondary school. Another approximately 15 boarders from Grade 1 to Grade 7 attend the Unit for Hearing Impairment at the Andreas Kandjimi Primary School about 3 km away. These learners, including Grade 1's with hearing impairments, have to get up very early in the morning and cover the distance to school by foot. It was reported that during 2018, there were two incidents in which a learner was accidentally bumped by a vehicle between the hostel and the school.

2.2 Operational rehabilitation centres

2.2.1 Rehabilitation Centre, Rundu Hospital



Rundu hospital houses a fully operational orthopaedic technology workshop, as well as a rehabilitation centre where an occupational therapist and an orthopaedic technologist work collaboratively. A multi-disciplinary approach is promoted after a mental status evaluation by the occupational therapist. The patient is then referred to the applicable service providers (e.g., social work, medical practice, educational psychology, occupational therapy) for intervention. The family of the patient is also involved.

The CLaSH poster on screening for speech, language and hearing challenges¹ is displayed in the rehabilitation centre.



2.2.2 Rehabilitation Centre, Eenhana Hospital

A physiotherapist and apparatuses for the physical rehabilitation of patients are available at the centre. Various posters related to early childhood development are displayed in the centre. Information about the screening of developmental delays² is the most prominent.



2.2.3 Rehabilitation Centre, Opuwo Hospital

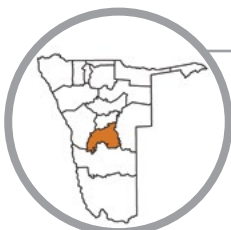
At present there is no physiotherapist or occupational therapist employed at the centre. All referrals are directed to Windhoek and Oshakati. One of the community liaison officers from the Office of the Vice President: Disability Affairs (OVP-DA) is an orthopaedic assistant. Provision and maintenance of mobility aids, as well as disability grant applications is an important aspect of their work.

Locally made physical therapy apparatuses for young children with Cerebral Palsy (CP) are available. Various posters related to early childhood development are displayed in the centre.



2.2.4 Rehabilitation Centre, Otjiwarongo Hospital

An occupational therapist runs the centre. It is well-equipped for physiotherapeutic services, however, the supply of materials and equipment for occupational therapy would improve service delivery. It was emphasised that rehabilitation consists of both medical and social rehabilitation. No posters on Early Childhood Development (ECD) or developmental disabilities are displayed.



2.2.5 Physiotherapy and Occupational Therapy Departments, Katutura Hospital

Most regions of Namibia are serviced by these departments. Presently there is only one physiotherapist in the physiotherapy department and two occupational therapists in the occupational therapy department of the hospital. Some cases from the latter department are sent to Windhoek Central Hospital. The occupational therapists at Katutura Hospital also render specific services to Windhoek Central Hospital when patients cannot be transferred. Posters with ECD information are displayed in the physiotherapy room.

Buses transport patients from regions to the hospital and back, on set days of the week. Some services are only available on specific days of the week and as a result, when an appointment is booked, the transport roster and clinic days are taken into consideration. Availability of seats is then determined, and if necessary, the caregiver and child will remain in the ward until the applicable service can be rendered.

The procedure is as follows:

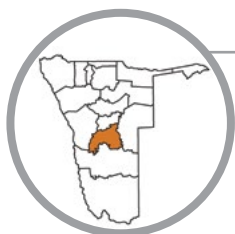
- referral from hospital/clinic/department
- check whether acute /chronic
- make a booking
- assessment consultation
- if physiotherapy is not available/ accessible for child where she/he lives, an exercise programme goes home with her/him
- follow-up/review by the doctor.

If CP is diagnosed, or the young child has a structural congenital anomaly, the physiotherapist trains the mother/caregiver on an exercise programme for the child. A follow-up visit to physiotherapy is scheduled for every three months. In serious cases a minor follow-up will be scheduled after one month.

Service delivery would be improved by appointing more professional staff. Specialised training in Specific Learning Disability (SLD)³ would also be helpful. The procurement process for wheelchairs/walking aids is complicated and lengthy at present, and its revision would improve rehabilitation services to impoverished families.

It is vital that a wheelchair is made available to a child who is in need of one as soon as possible, for the following reasons:

- A wheelchair enables correct bodily positioning, and the development of contractures is subsequently limited / prevented.
- As the child grows, it becomes progressively more difficult for caregivers to carry her/him around. A wheelchair provides mobility to go to school and the hospital etc.
- A wheelchair facilitates socialisation. The child is no longer isolated, but is given greater access to a social life.
- Having a wheelchair at the child's disposal also relieves the family members from the pressure of having to be continuously available. The child can learn to be more self-sufficient.
- A wheelchair gives the child access to community life. She/he can develop optimally due to sensory and cognitive stimulation and experiential learning.



2.2.6 Mental Health Unit, Windhoek Central Hospital

The facility is the only state psychiatric unit in Namibia that utilises a full multi-disciplinary team consisting of psychiatry, clinical psychology, social work and occupational therapy to render a comprehensive mental health service. Every professional member fills a particular role:

- Clinical psychology: psychological assessment, emotional support and parental guidance;
- Psychiatry: medication; and
- Social work: management of social circumstances.

With regard to children, referrals are made by medical doctors or clinic staff following their own screening or on the basis of an enquiry by an educational facility. Schools also refer children directly to the unit. On arrival, the child's medical history is recorded by the medical intern (tertiary training practicum). This will determine to which team member(s) the child will be sent. The patient file is shared, and team discussions are limited to complicated cases.

The International Classification of Functioning, Disability and Health (ICF) system of the WHO is not employed for identification, assessment and intervention. The Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) classification system is used and assessments are conducted for neurodevelopmental disabilities such as Autism Spectrum Disorder (ASD), Intellectual Disability (ID), and Attention Deficit/Hyperactivity Disorder (ADHD). The International Statistical Classification of Diseases and Related Health Problems

(ICD-10) coding system is used. When applicable, culturally appropriate adjustments are made to psychometric tests. Assessment for Specific Learning Disorder (SLD) is referred to MoEAC, due to the lack of suitable tools for evaluation at the unit.

2.3 Discontinued services

2.3.1 The Centre for Disability, Gobabis



The centre was established through funds from the Netherlands in 2004, which included a proposed mushroom cultivation project. However, the centre was closed down in 2008, after four years in operation, and transferred to the Ministry of Works and Transport. This was due to non-payment of municipal bills and interest that accumulated. The outstanding amount was never paid. The building is not in use presently.

Reopening this centre will serve the needs of the community well. A recreational facility for persons with disabilities would provide the space for occupational and other therapies to be rendered. As a result, fewer referrals to services in Windhoek would be made. A day care centre that is equipped to accommodate children with disabilities would not only enable their parents to earn an income but would also provide early childhood intervention by means of educational stimulation.

2.4 Noteworthy educational facilities

2.4.1 Nils Centre, Opuwo



Twelve learners with hearing impairments (7 to 23 years of age), have been taught in sign language by a volunteer since 2017. Learners who come from the region are accommodated with family or community members. Two senior students are enrolled at the Namibia College of Open Learning (NAMCOL) for Grade 12 in 2020.

The process of registration with MoEAC continues. The classroom is overcrowded and does not have electricity. The need for teaching materials was identified.

2.4.2 Dr Frans Aupa Indongo Special Care Centre, Oshakati



Forty-two children between the ages of 30 months and 18 years are cared for by the principal and four other staff members. Children from different regions of Namibia stay in the hostel on the premises. The facility is registered with MoEAC.

Children come to the centre through word-of-mouth. All children have disability grants, and the parents and caregivers do not make any contributions. The centre is dependent on donations. The principal noted that her own funds are used to run the school.

The principal who was trained at Oniipa and Windhoek, teaches the children and provides therapy. The space in the class is limited and educational equipment is required for teaching. According to her, 10 children are in need of wheelchairs, tricycles and wheel frames. A walking ring was donated for use by the youngest child (2 years and six months). Expansion of the centre is necessary. Each child is in possession of a Health Passport for their visits to a health facility.



2.4.3 Circle of Hope Private School, Ondangwa

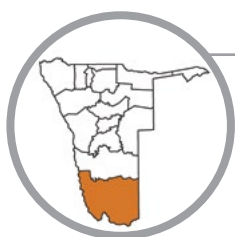
There are currently 10 children at the school in the age range 18 months to 13 years. The school specifically caters to children with Autism Spectrum Disorder (ASD), Down Syndrome (DS), Intellectual Disability (ID) and Learning Disabilities (LD's). Some parents relocated to Ondangwa to enrol their children at Circle of Hope. The school started in January 2019 with only two learners.

At present, three teacher assistants are responsible for individualised teaching of learners. Children pay school fees and specialised equipment is available for teaching. Swimming and music lessons are part of the curriculum. Due to the specific needs of children with ASD to develop social and communication skills, activities within the community are arranged for the learners. Generally parents of children with disabilities require counselling during the identification and intervention process.

The children are all covered by a medical aid. A service level agreement was negotiated with private facilities, and the children – if required – have access to the following services: paediatrics, occupational therapy, physiotherapy, and speech-language therapy.

As a result of the requirements regarding school buildings and premises, the curriculum, as well as inclusivity, registration at the MoEAC as a private school has been a challenge. Furthermore, while the principal has certification in specialised educational needs, she doesn't have a tertiary level teaching qualification.

It was reported that a Catch-22 situation has arisen: school registration is a prerequisite in order to obtain funding for new premises. However, registration is not possible due to the above constraints.



2.4.4 Step by Step ECD Centre and Learning Support Class, Keetmanshoop Disability Resource Centre

The OVP-DA runs a functional resource centre in Keetmanshoop accommodating the office of the Southern Association of the Visually Impaired (SAVI), an inclusive ECD centre/kindergarten and the learning support class of St Matthias Primary School. A support group for parents and caregivers of children with disabilities meets on a regular basis, but according to the members initiatives fail to progress beyond the planning phase.

A retired teacher with additional training works at the ECD centre. It is registered with MGEWCW and linked to the Namibian Association for Children with Disabilities. At present six pre-schoolers attend classes, but numbers increase significantly as the year continues. Children with and without delays or disabilities are welcomed at the preschool, and preference is given to the ECD group – the three- to four-year-olds. The current teacher capacity is not sufficient to accommodate the older age groups who require greater structure and advanced planning. An objective of the centre is to empower children and to promote inner strength.

The pupils in the St Matthias learning support class are reportedly placed by the MoEAC after assessment. A maximum of ten learners with cognitive delays in the age group 8 - 10 years is accommodated.



2.4.5 Stepping Stone Special Education School, Swakopmund

According to the principal, there is generally a limited understanding of the educational needs of children on the Autistic Spectrum (ASD) and/or with Intellectual Disability (ID). Various learners' enrolment at Stepping Stone was motivated by not having been able to adjust to other educational settings, due to their organisational structures or curriculum.

School fees are utilised to provide for the children's specialised educational needs and maintaining the standard of education. Some learners are sponsored. The school is registered with the MoEAC. The teacher-learner ratio is 1:3. While there are four groups of learners, each child essentially has an individualised educational programme based on the TEACCH⁴ academic curriculum and Floortime. Six learners have advanced to a classroom in which an adjusted mainstream curriculum is followed.

The school started as an ECD centre aimed at preparing children to go into mainstream classrooms with learner support. However, not all children with ASD are suitable candidates.

The school has a need for the professional involvement of a multi-disciplinary team, in particular speech-language therapy and occupational therapy.

A brochure to raise awareness on ASD is available in the following languages: Khoekhoegowab, Oshiwambo, Herero, German, Afrikaans and English.

2.5 Underutilised facilities



2.5.1 MoHSS Maternity Waiting Room, Opuwo

The maternity waiting room hostel is an underutilised facility. On average, only eight percent of beds are occupied. Clinics refer expecting mothers from rural areas to a hostel near to the hospital. However, families are often separated and subsequently find it hard to continue to support the mother. In many families there are insufficient funds to run two households, even if one is only temporary.

This facility has the potential to serve as a hostel for the learners from rural areas, for example at the Nils Centre (para 2.4.1). It can also serve as accommodation for parents, caregivers and children when the latter have to be assessed by a multi-disciplinary team at the rehabilitation centre.

3. ADDITIONAL RELEVANT PROGRAMME GUIDELINES, PRACTICE PROCEDURES AND PROTOCOLS

3.1 Guide to Initiating, Implementing, and Monitoring Community-Based Rehabilitation

The Ministry of Health and Social Service (MoHSS) compiled a protocol for Community-Based Rehabilitation (CBR), to be utilised by volunteers. According to the preface of this document: *“CBR focuses on enhancing the quality of life for persons with disabilities and their families, while meeting basic needs and insuring inclusion and participation. CBR was initiated in the mid – 1980’s and has evolved to become a multi-sectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services. CBR is implemented through the combined efforts of persons with disabilities, their families, communities, relevant government and non-government organizations.”*

The specific actions related to steps five to eight of the procedure described in the CBR Guideline have relevance:

- For conducting a door-to-door survey, a screening tool for children 0 to 17 years consisting of nine questions (Form 10) is utilised. In the event of a suspicion of or an observed disability, the mother or guardian is requested to take the child and her/his Health Passport to the assessment point.
- An individual assessment of the child is conducted by a team of professionals at the assessment point (Form 12) and a referral is made to (a) relevant service provider(s) (Form 13). It is suggested that the following professions are considered to form the multi-disciplinary team: physiotherapy, occupational therapy, orthopaedic technology, social work, nursing and medical practice.
- A slip attached to the referral form must be completed by the professional to whom the child was referred, indicating its outcome. This is given to the parent or caregiver of the child.
- Following the assessment, each child and her/his family are allocated to a CBR volunteer who is tasked with providing them with continuous support (Form 15) by means of regular home-visits.
- The CBR committee and volunteers are responsible to follow up on the referrals that were made during the individual assessments.
- The CBR committee and volunteers also have to continue to identify and register children with atypical development who have not been formally assessed before.

Evaluation

The guideline on bringing community-based rehabilitation (CBR) services to communities is straightforward and clear. However, there are some potential challenges to be considered with a view to effective implementation. First, a CBR committee and/or CBR volunteers should not be allowed to stand in for an assessment team when the latter is not available, as suggested in the manual. Volunteers are not bound to the ethical code of registered professions. Also, the disparity between volunteers’ expertise and that of professionals collaborating in a multi-disciplinary team is too wide. Substitution will consequently defeat the purpose of effective assessment as well as appropriate referral. Secondly, it is anticipated that a communication break-down could occur between the professionals to whom the child is referred by the assessment team, the rehabilitation officer and/or future service providers. It is recommended that the outcome is recorded in the child’s Health Passport.

3.2 Medical Report for Disability Pension

This form of the MGE CW is used to apply for a disability grant for a child in the age group 0 to 16 years. It has to be completed by a district surgeon or a senior medical officer from the MoHSS. It consists of two sections, a medical report on the disability and a medical examination. The latter includes the officer's expert opinion on the cause and effect of the disability. The questions are related to the daily functioning of the "patient", and her/his work capacity in terms of functioning, mobility, conducting own affairs and personal care have to be evaluated as either "normal" or "abnormal".

Evaluation

Apart from the medical examination, the questions do not have any bearing on the developmental context of children. How these questions will be interpreted by the official is open to subjectivity. Furthermore, the evaluation is based on the medical model. A human rights model by which criteria are formulated on the measure of limitation and restriction (ICF model) is considered to be more appropriate.

3.3 Application for maintenance grant for child under the age of 16 years with a disability

The application resorts under MGE CW. A registered social worker submits the completed form along with other documentation, to the Deputy Director of Child Welfare to apply for a disability grant for a child younger than 16 years.

Identifying particulars and details concerning the disability and educational history are recorded. The type of disability has to be indicated by opting for "Physical", "Mental" or "Other", and a medical certificate with further details has to be furnished. Regarding educational details, the types of schools are indicated as "normal" or "special" government school, or special school. In conclusion, the social worker has to motivate and recommend the disability grant by giving specific attention to the "extra and special needs" of the child related to her or his disability.

Evaluation

Although the requested information is regarded as suitable for evaluating the grant application, there is concern about the competency of a social worker to classify the nature of disability on the basis of the details given by a parent or caregiver and/or a medical certificate. International practice dictates that clinical diagnoses may only be made by suitably qualified professionals.

A review of some of the contents of the form is recommended, to replace discriminatory qualifiers such as "normal" and "special", and to bring it in line with the inclusive education policy of Namibia.

3.4 Disability Prevention and Rehabilitation Screening Tool

This screening tool appears in the Screening and Management Tool of the MoHSS (wd). Health workers (including community health workers) are trained to screen for adequate sight, hearing and speech for persons of all ages. If the person does not pass the screening test, she/he is referred to the rehabilitation worker at the hospital.

3.5 Health Passport

An updated version of the Health Passport has come into use. While no changes were made to existing questions, additional information is provided in the new version:

- Feeding recommendations for infants 0-6 months of age / 6-12 months of age and young children 12-24 months of age
- Examples of complimentary foods (from 6 months and older)
- Good hygiene
- Food and fluid recommendation during illness
- Assessment of TB in children
- Recommendations for Care for Child Development
- Counsel the Family about Problems in Care for Child Development
- Health Education: 0-6 months / From 6 months and older.

Evaluation

These are excellent guidelines for the primary health care sector to employ for counselling parents and/or caregivers in terms of care during the early childhood development phase. The section on “Problems in Care for Child Development” also serves as a screening tool for referral to other service providers if required.



Teacher with pre-primary learner at CLaSH

3.6 Learning Support Teachers' Manual

The introduction of the Learning Support Teachers' Manual (NIED, MoEAC 2014) (p.1), serves as a guideline for teachers to provide learning support to every learner in every phase of the education system. It outlines the identification of learning needs, reasons for learning difficulties and structuring learning support in the class room. The Learning Support Resource Book provides additional materials.

Barriers to learning can be external and/or internal to the learner (pp. 28-43). External barriers are found in the learner's environment. Internal barriers are identified according to neurobiological impairments, and warning signs are indicated. Reference is made to the importance of the identification of developmental delays as early as possible, in order for interventions to be planned to ensure that the child benefits from exposure to the educational environment by learning (p. 60).

The following professional role players are involved in addressing the challenges of learners who experience barriers to learning: CLaSH⁵ (p. 31), regional school counsellors (pp. 31, 35, 36), rehabilitation officers (pp. 31, 35, 38), developmental optometrists (p. 33), and state hospital eye clinics (p. 35).

"Readiness refers to the developmental maturity of a learner to start school. It includes all areas of development, e.g. social, emotional, physical and cognitive." (p. 69) Checklists are available to assess eleven "readiness" skills⁶ or areas of developmental delays. A variety of activities are suggested to develop these skills. Acquisition of these skills is considered to be a prerequisite for starting with the primary phase curriculum.

Evaluation

The outdated classification system of the WHO (International Classification of Impairments, Disabilities and Handicaps) (p. 27) has not been replaced in the second edition of the manual by the widely accepted International Classification of Functioning, Disability and Health, Children and Youth version (ICF-CY) (WHO 2007).

The diagram used to illustrate the learning process is ambiguous, and it does not correspond with the information in the text (p. 12).

Remedial teaching is opposed to learning support due to the underlying assumption of the former, of "fixing" or "changing" the learner by means of intervention (p. 5). Activities to assist learners to cross the midline are suggested for learning support (p. 23). Vision therapy is also a recommended form of intervention to improve a learner's eye muscle coordination and eye-teaming (p. 33). The Learning Support Resource Book (2014) contains additional teaching activities for the development of the various aspects of literacy and numeracy.

It states: *"In Namibia, there are special schools and units at mainstream schools for learners who are deaf, where they are taught to use sign language."* (p. 31) and also, *"Namibia has special schools for learners with severe visual impairment where they are taught to read braille."* (pp. 31-32) Special school placement is associated with learner exclusion and labelling (p. 5). Consistent with the ICF system that learners with hearing or visual impairments are generally best accommodated in resource schools, in which specific barriers are addressed, optimal learning/educational outcomes can be facilitated. As it is stated in the manual, *"There are many different ways in which a teacher can support the learning of a learner with specific learning difficulties in the mainstream classroom. All learners have the right to education. However, sometimes the needs of learners with severe learning difficulties may be better met in a Resource School."* (p 61) It is unclear which assessment procedure is followed to make decisions in this regard.

Teachers are guided to refer learners suspected of having intellectual impairments (ID) to the regional school counsellor for “*accurate identification*.” (p 36) It is unknown if regional school counsellors’ qualifications and level of registration allows them to perform this function. In the absence of further details, it is assumed that the learning support activities described in these manuals are sufficiently structurally adapted in terms of pace and content, for utilisation in the inclusive setting to facilitate the cognitive limitations associated with ID. If this is indeed the assumption, the specific educational needs of certain learners with ID will not be met during teaching. It follows that these learners’ right to education is met with disrespect.

The term “*specific learning difficulty*” is used (p 36) – not “*specific learning disorder*” (SLD) according to the international DSM-5 classification system (para 3.2.6). The causes stated for barriers to learning are based on the medical model, and the term “*minimal brain dysfunction*” (p 36) is not only outdated, it is not considered to be evidence-based.

Educational neglect, lack of parental support (p 36) and giftedness (p 38-39) are discussed under the section “*internal*” barriers to learning instead of “*external*” barriers to learning and in particular, the curriculum and teaching system (p. 29).

Autism spectrum disorder (ASD) (p.41) is described as a communication difficulty and not as a neurodevelopmental or psycho-social disability with often far-reaching implications regarding optimal functioning in the educational setting (para 3.4.5). Reference is made to the preference of many learners with ASD to be excluded from a group (p. 49), but ‘melt-down behaviour’ typical of ASD is not dealt with. Very important and useful information on first aid in the event of an epileptic seizure is provided (pp. 42-43).

“*Be inclusive. Excluding learners, or not understanding their needs and circumstances, can alienate them*” (p. 53). In so doing, the policy of inclusive education is applied in a way that actually excludes learners from participation in the educational system.



Meeting with parents of children with disabilities at Side by Side Early Intervention Centre

4. THEMATIC ANALYSIS

The following themes emerged from analysis of information discussed during the semi-structured focus groups and interviews.

4.1 Present identification and intervention system

4.1.1 In certain cultural groups, the discourse on delayed development and childhood disabilities plays a significant role.

- The young child's behaviour is not typically interpreted by the community as deviating from the norm, but is considered "supernatural", i.e., due to spiritual forces.
- There is a belief that the disability of a child is a punishment from God. It is the result of the parent or someone of the family having sinned.
- Atypical development and/or disability can also be regarded as the result of witchcraft.
- Some community members believe that disabilities are contagious. This belief has negative implications and results in isolation. It is said that a pregnant woman should not look at a person with a disability, as the foetus she carries would be affected. Also, neighbours of a child with a disability will be reluctant to look after her/him when the parents have business to attend to.
- When parents seek assistance from a service provider, it is seen as an admission that they are unable to care for their child.
- If a baby is born with a disability, it is expected of the parents to accept her/him as the child God wanted them to have.
- Disability and atypical developmental aspects are understood as static, i.e. unchangeable and unmodifiable.
- Some individuals are under the impression that educating a child with a disability is a waste of time.
- There is a stigma attached to the Mental Health Unit of Windhoek Central Hospital (para 3.2.6) – only "mad" or "crazy" people are referred to the unit.

4.1.2 The Health Passport is the primary record of a child's developmental history

- While there is no antenatal care after a homebirth, information of the birth is not recorded in a Health Passport.
- Depending on tradition, the new-born's name is only entered in the Health Passport after the naming ceremony. Some children have two Health Passports.⁷
- In some families the same Health Passport is used for more than one child. A child may be issued more than one Health Passport due to the parent forgetting the original at home or claiming that it has been lost. The birth dates may also differ. Consequently, biographical details are inconsistent, and/or the developmental history becomes fragmented and/or incomplete.

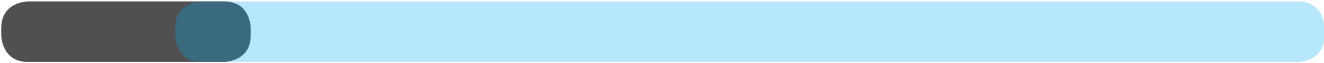
- With an eventful developmental history, another Health Passport will be issued once the first document is full.
- Unless information is stored electronically, a child's developmental information will be permanently lost when the Health Passport is destroyed either through negligence or by accident.
- Caregivers do not always understand the importance of having a comprehensive account of the child's developmental history.

4.1.3 Identification of developmental delays and/or disabilities can happen in various ways

- During pregnancy, the mother is screened during clinic visits. A sonar is done to detect atypical prenatal development.
- The nursing staff and medical doctor detect a physical or genetic anomaly at birth, or the new-born is categorised to be "at risk" on account of traumatic birth markers associated with atypical development.
- It is identified by clinic staff during the course of scheduled developmental screenings for every child from birth until school-going age (according to the Health Passport).
- Community-based rehabilitation (CBR) volunteers, community health workers or OVP-DA liaison officers may identify challenges during outreach programmes that include formal screening for sensory impairments; through coincidental observation of developmental issues and/or in response to the enquiry of a parent, caregiver or community member in this regard.
- Delayed or varied development is picked up by a professional when the child visits the clinic, is enrolled at an educational institution or a family member visits a social worker.
- A social worker may suspect a developmental delay or disability when the young child is observed during a home visit.
- The parent or caregiver is concerned about the child's development and reports her/him to a health facility.
- The parent or caregiver consults with a social worker, because of the challenges she/he is facing in caring for the child.
- The educarer at the ECD centre or the pre-primary teacher realises that a pre-schooler has a hearing and/or speech impairment.
- At 5 or 6 years old, the pre-primary teacher observes the child having challenges with drawing, speaking, sight or hearing.

4.1.4 Professionals can respond in different ways:

- Medical or nursing staff might not disclose the findings or their concerns to the mother.
- The staff at the maternity ward explain the new-born's health condition to the parents or alert them of their concern that the infant is "at risk".⁸ A note is made in the Health Passport, and/or a sticker is put in the



document to alert future service providers of the infant's vulnerability. The importance of monitoring the infant is emphasised to the mother, and a follow-up appointment is scheduled for six weeks thereafter.⁹

- The clinic nurse does not respond because she/he is unaware of the screening tools available or not trained in what steps to take.
- The clinic nurse trains the mother in keeping track of her baby's developmental milestones and requests her to return to the clinic if she observes she/he is not developing accordingly.
- According to their training, CBR volunteers refer the child to the multi-disciplinary assessment team.
- The parent or caregiver is referred to MGECW to apply for a disability grant.
- Medical tests are performed and a diagnosis is made and if applicable, the child is referred for operative procedures.
- A social worker is tasked to give support to the parents and family.
- The child is referred by an official to a physiotherapist or occupational therapist of a health care facility, or to the audiologist/speech-language therapist at Windhoek Central for assessment.
- The professional informs the parent or caregiver, there is no reason for concern; the child will "be fine" or "grow out of it".
- Professionals do not refer, because they do not believe intervention will make a difference.
- The educator or teacher does not act on the pre-schooler's atypical development on the basis that it will be addressed as soon as she/he enters formal school.
- The teacher requests the parents to seek help and works with the child individually.

4.1.5 The parents or caregiver can respond in various ways

- Because the parent is unaware of the concerns about her child's health condition, she/he does not respond.
- The parent or caregiver does not take the child for assessment as a result of cultural beliefs associated with disability (para 5.1.1) and/or lack of understanding of the effects of early intervention.
- The parent is in shock and is emotionally unable to respond appropriately to the instructions and/or guidance of service providers.
- The parents or caregivers limit the child to the home. This isolation can be motivated by overprotection, shame or neglect.
- The parent or caregiver is not open and forthcoming in sharing information about the child's development with an unfamiliar person.
- The parent first seeks alternative forms of help, e.g. from a traditional healer or the church.

- Owing to resource challenges such as lack of finances, transport and/or accommodation, the parent or caregiver cannot take the child to the place of referral.
- The parent borrows or saves up money and consults with a private practitioner to have the child assessed.
- The parent seeks medicine to “cure” the child.
- Parents access services for assessment in South Africa if they have the financial means.
- The parents or caregivers develop a working relationship based on trust with one or more service provider, and act upon therapist instruction and/or guidance.

4.1.6 According to existing policies and protocols, the following service providers are involved during identification (diagnosis) of developmental delays and/or disabilities

- The multi-disciplinary assessment team that should be utilised by CBR volunteers, consists of a medical doctor, occupational therapist/physiotherapist, social worker and nurse.
- The MoHSS outreach team usually consists of an occupational therapist, medical rehabilitation officer and education officer.
- The OVP-DA liaison officer acts as a referral agent when parents or the caregiver approach the office.
- Medical (occupational therapist/physiotherapist) or social (social worker) rehabilitation officers deal with physical disabilities (including CP, clubfoot), and traumatic brain injury (TBI), after referral from a medical doctor or nursing staff.
- Audiologists are consulted for hearing impairment, and speech-language therapists for speech and communication limitations, as well as hearing impairment.
- Parents of young children who are suspected to have ASD are referred for a multi-disciplinary assessment by a paediatrician and/or psychologist, speech-language therapist and occupational therapist.
- A diagnosis of ASD or ID (i.e. psychosocial disabilities) is made by a clinical psychologist at Windhoek Central Hospital or by private practitioners including paediatricians, psychologists and psychiatrists.

4.1.7 Developmental variations

- Generally more attention is given to the developmental needs of deaf and hearing-impaired children.
- Albinism, visual impairments, the psychosocial disabilities ID and ASD are neglected.
- Controversy exists among decision makers whether albinism should be categorised as a disability.
- Physical disability can also be caused by physical abuse.
- The distinction between CP and physical disability resulting from illnesses such as poliomyelitis or serious accidents is not commonly understood.

- The educational needs of a child with a physical disability are not recognised as being different from the educational needs of a child who is confronted with cognitive barriers to learning as a result of atypical neurodevelopment.
- The term “learning difficulties” is incorrectly used to refer to cognitive delays and/or ID. Learning difficulties or learning disability is the umbrella term for specific learning disorders (APA 2013: 66-74), i.e. neurodevelopmental challenges with the mastery of the scholastic skills reading, writing and/or numeracy.
- Malnutrition plays a significant role in many households. Malnutrition, as is the case with the abuse of alcohol during pregnancy, is also a preventable cause of delayed foetal development.

4.1.8 Application procedures for a disability grant

- A service provider refers the young child to MGE CW, or the parent independently seeks assistance from the social worker.
- The social worker requires the birth certificate of the child, and the parents’/guardians’ documentation to start the application procedure.
- A medical officer at a state health facility completes the prescribed form (para 4.2).



Learner reading in Braille

- The social worker compiles a report after an assessment and home visit.
- The district surgeon approves or disapproves the application.
- Should the application be disapproved, the social worker can motivate revision.
- The documentation is sent to the Office of the Prime Minister.
- It takes approximately six months to one year for processing to be completed and for the first payment to be made.

4.1.9 In order to ensure effective service delivery, the following procedure is followed when a child is referred from Otjiwarongo Hospital to a referral hospital in Windhoek

- The health facility is contacted to get clearance for the referral.
- The referring practitioner writes a referral letter.
- The parent or caregiver and the child travel by ambulance to Windhoek.
- Upon return from Windhoek, after the consultation, a nurse at Casualty receives them on arrival at the hospital.
- The nurse notes the treatment prescribed for the child and checks for follow-up appointments.
- The nurse discusses the outcome of the referral with the parent or caregiver.

4.1.10 Individual stakeholders use variations of the 'at-risk sticker programme' from Zimbabwe

The policy operates as follows:

- A green sticker is put on the “Health Passport” when the Apgar score is low or when a developmental delay is detected.
- The pre-schooler is scheduled for follow-up at the clinic every three months. If the child is no longer at risk, she/he is taken off the programme.
- Specific staff are allocated for the programme – in the maternity ward and a nurse in the outreach team. Mini assessments are done, home programmes are given and follow-up bookings are made.

4.1.11 There are different reasons why the developmental course of at risk children are monitored

- Disabilities such as ASD and ID are “invisible”, i.e. not necessarily observable for many. Moreover, it can take time to unfold and be identified.
- Some therapists believe that they should be more alert and thorough during a routine check-up of an at risk baby.

- Some of the “cures” used by traditional healers can impact the child’s health status negatively, to the extent of contributing to disability.
- When confronted with their child’s developmental challenges, some parents or caregivers develop an attitude that the child is “useless” and leave her/him to be.
- Parents and caregivers do not necessarily process information shared with them by a health care provider about the child’s situation immediately or accurately.
- Parents and/or caregivers develop an understanding of their child’s health condition and are subsequently guided over time to be competent carers.
- When necessary, a timely referral to the appropriate service provider can be made.
- Parents or caregivers are not necessarily aware of the importance of follow-up and follow-through of treatments. The effect of successful intervention can be maintained through monitoring.¹⁰
- The sooner medical intervention goals are achieved, the lesser the chance for complications to develop. Less time is spent in health facilities, and more time with the family at home and in the community with peers.
- If caregivers do not take proper care of the young child’s prosthesis and/or mobility equipment, the child does not have the continued benefit of its corrective/facilitative purpose.
- Under the impression that the developmental delay is temporary, and that the child will “catch up” some time, the parent or caregiver postpones enrolment at an ECD centre, kindergarten, pre-primary class or Grade 1.
- According to the promotion policy, allocation for learner support is only made in Grade 3. When a young child is monitored, her/his individual educational profile will be available to guide decisions regarding equitability in Grade 1 already.
- The better the child’s development is understood, the more functional intervention can be planned.
- The record keeping during this time establishes a developmental history / baseline profile for the individual child.

4.1.12 Presently access to intervention services for young children with identified developmental delays and/or disabilities is compromised

- The severity of the delays and/or the disability often determines whether action will be taken or not.
- There are practical reasons making it impossible for parents or caregivers with a low SES to access intervention services for their young children:
 - ➔ The geographical distance between home and the health facility where the service is available¹¹ has a direct correlation with time spent away from home (and outside the labour market) and financial expenditure. The parent or caregiver cannot afford the costs of transport, accommodation and subsistence involved

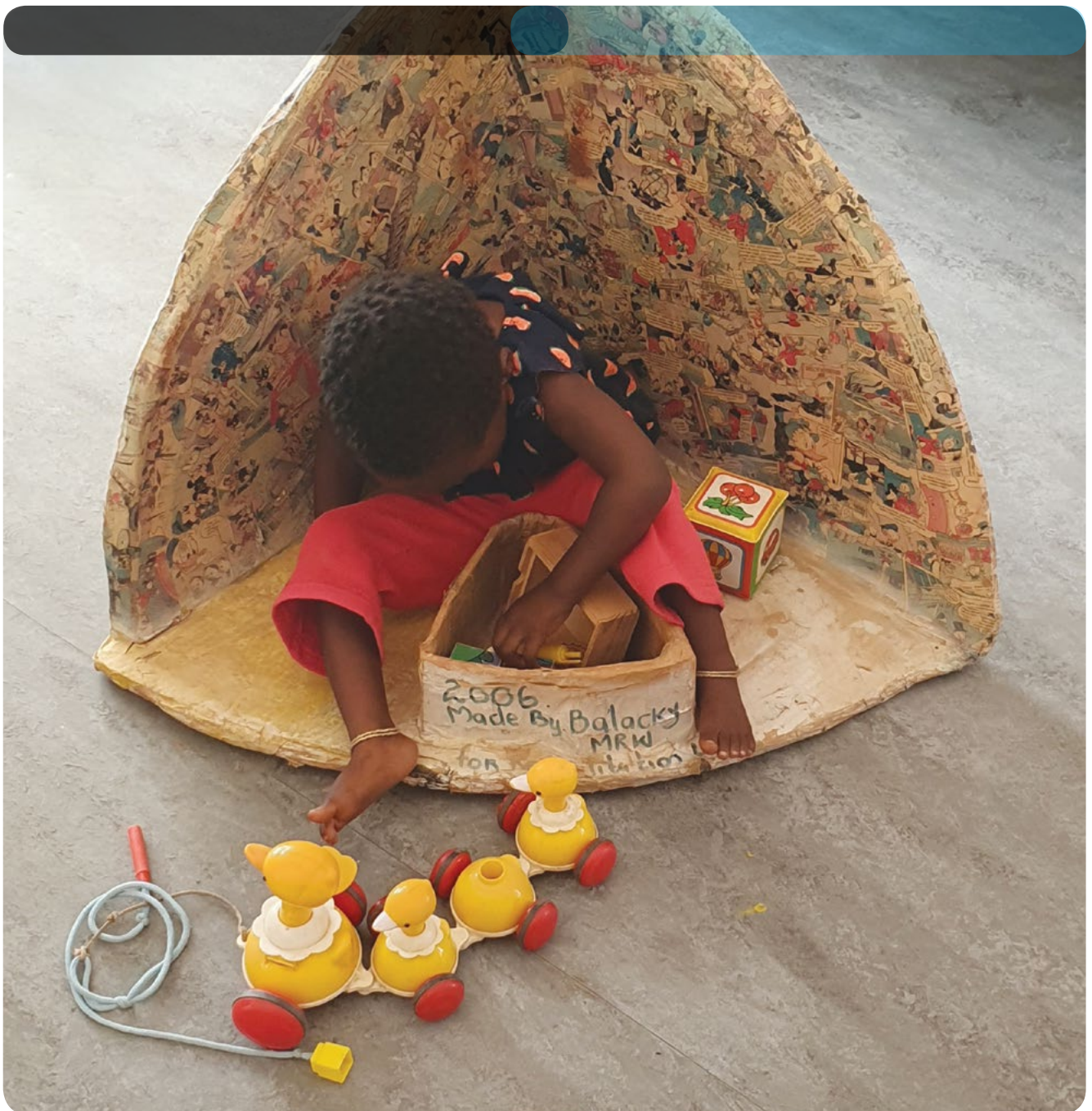
to visit the therapist; all the more when it is not a once-off visit. Furthermore, for as long as the parent attends to the child's needs away from home, they are removed from the place where the family's living is earned.

- Although effort is made at rehabilitation centres to synchronise available ambulance services from some regional hospitals to the clinic days at the Windhoek hospitals, it is not guaranteed. The ambulance service is not offered in all regions.
- There are many vacancies for occupational therapists and physiotherapists at the regional rehabilitation centres.
- Therapists are unable to keep up with the demand for their services and have to prioritise cases.
- Many parents do not understand the difference between identification and follow-up sessions for intervention. From their point of view, identification is intervention.
- For some young children, disability is “created” due to inadequate or lack of intervention.¹²
- Parents of young children with severe disabilities are advised to find a “resource” pre-primary school that can accommodate their specialised needs, although such facilities are basically non-existent particularly in the rural areas of Namibia.
- Although still on a limited scale, facilities for pre-primary children with hearing impairments are mostly available.¹³
- The efficiency of the current system for procurement of assistive devices runs counter to the purpose of the early identification and intervention. For example, a child with limited or no mobility is kept dependent on a caregiver to move around owing to cumbersome administrative procedures to have a walking frame or wheelchair issued. For the same reason, caregivers have to physically carry a child around.
- Although the expertise of speech-language therapists in AAC¹⁴ is indispensable with regard to facilitating the communicative competency of children with ASD, it is not available.
- The input of an educational psychologist when individualised planning is done for children with ASD and ID is not obtainable.
- Pre-schoolers with ASD or ID generally do not have access to ECD centres or pre-primary classes catering to the unique needs associated with these conditions.
 - For a number of young children with ASD, appropriate specialised intervention during early childhood creates the window of opportunity to enter into mainstream education at a later stage.
 - Learners with ID will benefit optimally from inclusive education when the window of opportunity during early childhood is utilised for school readiness preparation.
- The parents and families of children with severe delays and/or disabilities feel especially overwhelmed and are in need of counselling and support.

4.1.13 Parents or caregivers are empowered by the flow of information between them and service providers

- *“A mother knows her child best, she is like a fire detector. The therapeutic team needs her input.”*

- A diagnosis or description of the developmental delay/disability makes information available to parents to understand the nature of their child's health condition, make sense of it and come to accept it.
- Assisting the therapist to make equipment or being trained in using a home programme to manage the condition and/or stimulate the child's development, strengthens the parent's and/or caregiver's ability to care for the child.
- Explanations should be straight-forward in everyday language, as well as evidence-based and accurate.
- The knowledge and insight gained by the working relationship, guides informed decisions with regard to issues such as the child's education and an internal locus of control¹⁵ is cultivated.



Homemade corner seat for children with disabilities

- Parents are not only respected as the child's primary caregivers, but also held accountable for her/his quality of life.
- They are enabled to evaluate all aspects of service delivery to their child in terms of the needs related to her/his individual developmental profile.

4.1.14 Families of children identified with developmental delays or disabilities require different forms of support

- The first priority of impoverished families, is to find and maintain a means of survival. In this process, children with delays and/or disabilities may be neglected.¹⁶ Abuse may result from the frustration of dealing with an extremely stressful situation.
- The caregiving system gets reorganised following identification: Children are left in the care of grandparents in rural areas while the parent moves to town to find employment. The health condition and age of grandparents are some of the factors which determine to what extent they will be able to fulfil the child's general and unique nurturing needs. Grandfathers often replace absent fathers in the lives of children with disabilities.
- Learning that a young child has developmental delays and/or a disability, is often distressing for parents/caregivers and may need counselling and support.
- The parents of a child with a disability often find themselves in a double bind in having to earn a living and take care of the special needs of their child.¹⁷ The financial responsibility associated with the caregiving of a child with a disability is a primary cause of anxiety.
- Complexity is added to the caregiving system if the parent is also living with a disability.
- Parents/caregivers who need to work outside of the home may entrust the care of the child with other young siblings and/or abandon them alone at home.
- If a caregiver cannot afford transport, the child is likely to miss a scheduled appointment at the health facility.
- Without mobility equipment or assistive devices, children with physical or sensory disabilities have to be physically carried, at times over long distances.
- Many ECD centres are unable to provide the level of care that a child with a disability requires.
- Many ECD centres are run on a voluntary basis. The staff may not be trained and/or may be ill-equipped to accommodate young children with disabilities.
- The need to protect these often immature and vulnerable children, prevents parents and caregivers from sending them to distant educational institutions.
- Being employed as educators or assistants at ECD centres for young children with delays or disabilities may be appealing to some adults with disabilities.

- Parents of children with severe disabilities can develop burn-out and may require counselling and relief from their caregiving duties.
- Self-sufficiency of parents should be encouraged where possible, through income-generating activities such as selling food or crafts.
- The attitude and support of family, employers, the community and professionals all play a significant role in the parent's understanding and acceptance of the child's unique development.

4.1.15 The transition from preschool to Grade 1

- Many children with developmental delays and disabilities are kept home; they do not attend ECD centres or other pre-primary school facilities.
- The prospect for children with disabilities entering mainstream or inclusive education in Grade 1 is substantial for those who have already attended inclusive or resourced ECD facilities at a young age.
- Due to limited funds and unavailability of transport, contact between parent/caregivers and the Grade 1 child with a disability in a school hostel is usually limited to school holidays and therefore they may choose to send their children to school at an older age when they are more mature.¹⁸
- Children with disabilities between the ages of 4 and 6 who have not been enrolled at ECD centres or pre-primary classes are disadvantaged in Grade 1.

4.2 Identified strengths, barriers and gaps

4.2.1 Strengths

Regional disability-awareness is raised by the relevant ministries on an annual basis.

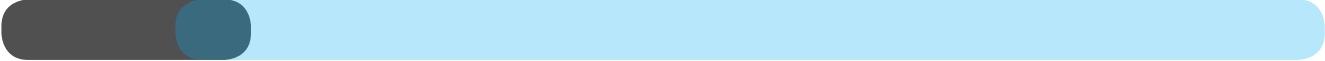
Birth registration has improved as a result of the e-birth notification system that was launched during 2017. The Health Passport, reflecting the child's developmental history, is widely used among service providers.

In many regions, CBR volunteers are generally considered to be the frontline workers in communities. Due to community members' familiarity with them, the volunteers play a constructive role during the identification process of developmental delays or disability for some children. Community health workers also play an important role in monitoring children's developmental track, e.g. doing screening. They are medically trained and collaborate with role players from other ministries. The collaboration between the OVP-DA and MoHSS is easier when the OVP-DA liaison officer is housed at the rehabilitation centre or hospital.

Some hospitals have a fixed transport schedule to and from Windhoek hospitals.

The Pontsetti system to identify and treat clubfoot is functional and effective. Orthopaedic technicians conduct some follow-up visits at the child's home. The services of a plastic surgeon are available at Rundu Hospital for work on cleft palate and corrective dentistry.

Social workers hold a key position in relation to the child with delays/ disabilities and the family. Disability grant applications and MoHSS and MGEWC services provide access to social support and counselling.



When an application is made for a disability grant at Rundu Hospital, the child is assessed by a multi-disciplinary team consisting of a medical doctor, physiotherapist/occupational therapist and social worker. The outcome of such assessment allows for individualised planning of intervention services.

According to the policy, an allocation for a grant on the basis of a temporary disability can be made.

Children with disabilities are registered on a database of the OVP-DA. In an attempt to preserve medical records of children with disabilities registered at the rehabilitation centre at Opuwo Hospital, a copy of records is scanned and stored in a computerised format.

Following personal experience with their child, many parents take initiative to improve the quality of life of other children with disabilities. One parent launched a class in which sign language is used as the modality of communication, while another parent established a group for children with CP in preparation (0-6 years) or support (6-12 years) of their school attendance.

“Quantity in numbers demand quality of service”: the limited number of therapists available in Namibia to provide services to a great number of children with disabilities, necessitates that therapists empower parents and/or caregivers with knowledge and training so that they are able to assist their children themselves.

MoHSS has created and approved state posts for the therapies – physiotherapy, occupational therapy and speech-language therapy – that are required for a multidisciplinary team approach to disability. The first group of physiotherapists and occupational therapists will graduate from UNAM at the end of 2023.

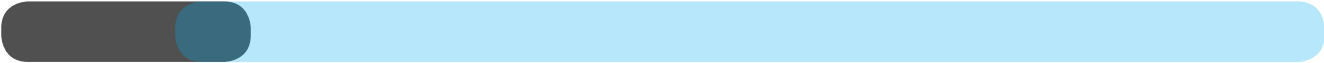
All children, irrespective of the kind of disability are accommodated in pre-primary classes at schools in some of the regions. Their presence in the educational system favours the prospect of their developmental needs being addressed.

The policy of inclusive education is already operational at educational institutions in Namibia. MoEAC is approached to do the placement of children with developmental challenges and disabilities. Existing resource units or schools play a crucial role in fulfilling the specialised educational needs of certain learners with visual and hearing impairments, as well as with neurodevelopmental disabilities. Learning support classes are also functional at various schools in the regions of Namibia. Education for deaf and hearing-impaired children appears to be adequately structured in Namibia. The curriculum of school beginners is focused on learning orientation.

4.2.2 Barriers

Namibian conditions are harsh, with extreme weather and mostly gravel roads in rural areas. Personal factors can also prevent parents from accessing services for their child who is developmentally delayed or has a disability. For example, still coming to terms with their child’s health condition can play a role.

Since the rehabilitation centre was transferred from MoHSS to the OVP-DA, the working relationship between therapists and the liaison officer changed. Apart from no longer being obligated to collaborate, they are each bound to a different budget, administrative system and ministerial schedule. For example, coordination of trips to the communities using one vehicle (suitable to deliver mobility equipment) is very difficult, if not impossible. At some rehabilitation centres therapeutic services have also taken a backseat. This fragmentation is not conducive for proper teamwork/ multi-disciplinary collaboration. The cuts in ministerial budget for transport in the regions does not allow officers to work in the communities.



Because the CBR volunteers do not get some form of incentive, they often do not remain motivated to perform their duties. Many volunteers move into paid positions after CBR training. In some communities the CBR programme is no longer operational.

Due to budget constraints, staff shortages, unavailability of transport and/or inaccessibility of some areas, and unmanageable caseloads due to inadequate staff deployment, stakeholders are unable to fulfil their function within the service delivery system. Furthermore, due to a lack of coordination among role players, parents or caregivers are sent from one service provider to the other. This creates the perception that role players are inadequate and/or insensitive to their vulnerability. When service providers treat parents or caregivers with disrespect, they do not cooperate as they are supposed to.

Parents or caregivers have reported negative experiences when accessing services in Windhoek. Besides having to travel long distances, they may need to stay longer in order if appointments are delayed or rescheduled. The ambulance schedule may not correspond with child's scheduled visit to the health facility. The ward where caregivers and children stay is sometimes overcrowded and not adequately staffed to cope with behavioural challenges. The waiting list for an appointment for a speech and language assessment at the Ear, Nose and Throat (ENT) clinic at Windhoek Central is very long.

Another barrier to continuity of service provision is the turnover of doctors. A new doctor will not necessarily continue the treatment procedures of a previous doctor. There may even be no doctor when the patient arrives for follow-up.

The human resources capacity is not nearly sufficient to provide the services associated with early identification and intervention of developmental delays and disabilities. It is of limited value if awareness in terms of disability is raised, but the state does not have the capacity to respond with appropriate service provision and follow-up. Similarly, therapists cannot respond appropriately during the window period of early childhood development as a result of a lack of or limited resources, including human capacity.

Decisions with regard to intervention are based on insufficient knowledge about the different kinds of disabilities. Resources that are available for intervention do not address the particular needs or specific issues associated with the child's developmental challenges. Various stakeholders do not realise that some disabilities are complex and require expertise to manage competently. A collaborative system between different role players in the field is therefore not operational between speech-language therapists, social workers, psychologists and teachers.

Service delivery is often hindered by neglectful parents or caregivers. For example, some parents do not use available opportunities for parent education, or they do not take responsibility for their child's education. A further barrier to communication and learning for young children with hearing and/or communication disabilities or challenges is that the parents, caregivers, teachers and the children cannot use or understand sign language.

Parents who are unemployed and/or impoverished often do not have the finances to give their child the care they require. Most services are not provided locally. Parents cannot afford the transport to access the services that their children require. They also cannot afford accommodation and subsistence when they have to stay over for services at a health facility. Additionally mobility equipment is expensive to buy.

An application for a disability grant cannot be made without a birth certificate. The disability grant amount does not cover the basic expenditures associated with the developmental needs of children with a complex disability or multiple disabilities.

Many educational facilities are not accessible for children with physical disabilities. Some educarers or teachers are reported to have stigmatised children with varied development, and giving preference to those children who do not require additional support. Some parents or caregivers do not feel free to send their children to an ECD centre or school, because the children do not feel comfortable in the learning space or accepted by their peers.

The level of training in learner support does not allow educators to modify learning material according to the specific educational needs associated with the child's disability and her/his functionality level. It is expected of educarers/pre-primary and primary teachers to teach children with different disabilities irrespective of their varied educational needs but the reality is that these cannot be addressed simultaneously.

ECD centres or schools turn children away because they cannot accommodate the severity of the delay/disability. Alternatively, young children with developmental delays or disabilities generally do not attend ECD centres or pre-primary classes. This age group is too young and vulnerable to be considered for hostel placement. Children with ID are often not sent to school.

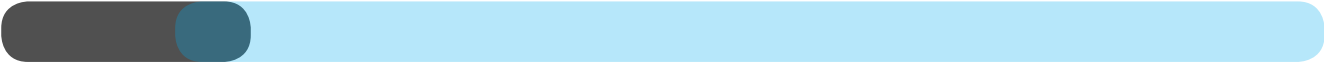
4.2.3 Gaps

There is a need for prenatal and antenatal health education clinics to be held in Namibia on a regular basis. In Kenya, for example, a maternity clinic is held weekly, consisting of a lecture/talk on different topics. Early identification of delays is an important topic. Follow-up appointments for new-borns are scheduled on clinic days and mothers are encouraged to attend.

There is a gap between screening policy and its implementation. For example, screening for hearing impairment in Grade 1 should be implemented dutifully. It is vital that nurses at clinics are alert to the impact of chronic otitis media on language development.



Pencil box for children



According to the CBR guidelines, a multi-disciplinary team travelled inland for a week at a time to do assessments. However, this system was terminated due to a “budget cut”. At present, school counsellors are expected to perform this function, and do the follow up post-identification.

There is a gap in communication between referring teachers and service providers. For example, a school counsellor refers a learner to the rehabilitation centre for a “medical assessment” instead of requesting a “developmental assessment”. At times, the teacher’s referral to the state doctor contains irrelevant information and/or interpretation of behaviour.

Stakeholders are unaware that the needs of children with disabilities vary – not only with regard to the nature of the disability, but also according to personal circumstances. Parents, caregivers and professionals alike, do not always know which services these children should be referred to.

There has to be an integrated system in which available resources are optimally utilised for monitoring and intervention. Teachers expressed the need to collaborate with the child’s therapists (speech-language therapist, occupational therapist, physiotherapist and psychologist) and be guided by them regarding learning support and other interventions. There are gaps in terms of service provision due to posts not being filled. There are no psychologists assisting families and educational institutions with managing psychosocial disorders.

Currently services for intervention are not available. Providing services on a regional scale, will greatly assist the children in need. There is a need for a “disability clinic” in each region. The invisible neurodevelopmental disabilities (e.g. Autism Spectrum Disorder (ASD), Intellectual Disability (ID), Traumatic Brain Injury (TBI), Specific Learning Disorder (SLD)), albinism and visual impairments are neglected at present. Parents, caregivers and their children from remote areas should be allocated accommodation and support services while accessing services at the clinic.

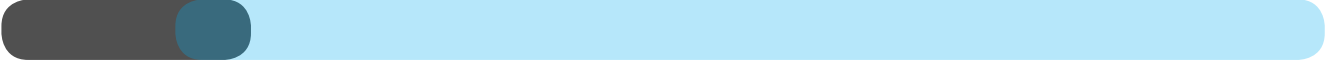
Rehabilitation for the visually impaired is not serviced by the ministries but is referred to private practitioners.

The following professionals should be considered when forming functional multi-disciplinary teams: social workers, audiologists, speech-language therapists, psychologists, occupational therapists, physiotherapists and orthopaedic technicians. A sufficient number of the key role players should be employed by the ministries on a regional level in order to accommodate the full case load.

A multi-disciplinary approach requires a case management structure and follow-up has to be done in order to avoid the child getting lost in the referral chain. Furthermore, an electronic system for professional communication will strengthen the information-flow from one system to another. In this way, all information pertaining to the child’s development and/or disability is centralised and recorded for future reference. A record of the child’s early history is important, especially in cases of ASD and ID.

There is a need for ECD centres and pre-primary classes that accept pre-schoolers with delays and disabilities. Appropriate day care facilities for young children with disabilities are also needed. ECD centres and pre-primary classes should employ teacher-assistants. Play centres should also be required to accommodate children with disabilities. Education institution staff have to be adequately skilled to cater to the learning needs of children with delays and disabilities.

The policy for inclusive education has been implemented in Namibia, yet learners with physical disabilities do not have access to many of these educational institutions. Building regulations must stipulate that no educational institution may be erected unless it is accessible to persons with disabilities. There is a need for specialised (resource) facilities catering to the needs of the different disabilities. The budget allocated to resource schools should be protected and not be misused or mismanaged.



Parents of children with delays or disabilities in the rural areas should receive financial support from the government to be able to access education for their children. Accommodation at inclusive school hostels is not sufficient for the number of learners from the rural areas. Specialised training should be given to matrons of the hostels. Provision should be made for a number of supporting staff who are able to give individual attention to the school beginners / young children.

Attention should be given to attachment relationships. School beginners/ young children have to stay in the hostel for the whole term. There is no transport available to take them home at least once a term. Young children with hearing impairments generally seem to have a strained relationship with their parents. Communication is poor or nonexistent if both parties do not have a command of basic sign language as children go to hostels at an early age. It is therefore important that parents and young children start to communicate in sign language as soon as possible.

Reliable school transport should be arranged for unaccompanied deaf and hearing-impaired learners who have to walk long distances, as their safety is compromised.

Communities require resource centres where specific services associated with disabilities are available. Persons with disabilities can spend time on recreation and/or play, and it may also have facilities to spend the night. It could also be utilised for training as well as other activities. Parents need training on how to play with and assist their children with home exercises. This centre could host team members, such as the social workers and nurses.

Disability-friendly means that the environment is adjusted according to the needs of the child or learner. Teachers often do not “understand” the world of a child with a disability.

Able-bodied people are sometimes insensitive to or unaware of the notion that children with disabilities gain a sense of comfort from their association with other children with disabilities.

Training has been identified by the participants as the most prominent gap with emphasis on the following topics or themes:

- the rights of children with disabilities
- parental awareness of delayed development, developmental disabilities and/or available services
- stories of hope for parents and families – developing the potential of children with disabilities
- terminology for developmental delays and disabilities for use by school counsellors
- the appropriate identification of developmental delays and disabilities
- screening for and identification of ID
- guidelines for parents and caregivers on social integration of the child upon return from health care facility
- introduction to basic sign language for parents, caregivers and service providers
- specialised training for inclusive education teachers
- a multi-disciplinary team approach

- training manuals on early childhood development and the Health Passport for use by nursing staff during prenatal clinics
- basic care and interaction skills training for educarers
- disability-related first aid training in the event of eg. epileptic seizure.

Pamphlets on early childhood development are not available in any of the major indigenous languages.

5. PROSPECTIVE COLLABORATION ON TERTIARY LEVEL

Three lecturers from the Faculty of Nursing at the Oshakati UNAM campus attended the focus group on 29 January 2020 at Oshakati Hospital, where they indicated their interest in collaborative research activities with a view to developing manuals on early identification and early intervention. This request was formally included in an e-mail to the researcher on the same date.

Collaboration with academics in the nursing field will strengthen the sustainability of the project. Stakeholders are strategically placed in primary health care to enhance the quality of early identification and intervention services for children with delays and disabilities. These manuals would be useful for tertiary education in Namibia.



Homemade standing frame for standing exercises

Three versions of an electronic questionnaire on educational institutions were developed and e-mailed to representatives from the following target groups:

- Educational institutions
- Disability support groups/ organisations
- Professionals

Two resource schools – one private and one state – responded. As this target group was well represented in the focus groups during field work (Section 2), only additional information provided by these respondents is reported on. The demographics of the other two research groups are presented in Appendix 3 (Disability support groups/ organisations) and Appendix 4 (Professionals) respectively. The main themes that emerged from their responses are presented below.

6. EDUCATIONAL INSTITUTIONS

6.1 Early identification and intervention

One respondent highlighted that early identification of challenges with fine motor development means that the child can benefit sooner from occupational therapy. The EIEI system can be enhanced by educator training, specifically on identification of developmental delays and disabilities.

6.2 Preschool-Grade 1 transition

An estimated 80 to 95% of learners in Grade 1 at these schools did not attend an ECD centre or pre-primary school. Both schools have pre-primary intervention programmes which are facilitated by the staff. The focus is on readiness to learn; school readiness; mastering the activities of daily living (including personal hygiene) and social skills.

One school has hostel facilities for children from six years. It has to be considered that these children are not necessarily independent with regards to toileting, washing and feeding.

6.3 Multi-disciplinary approach

One of the schools utilises a multi-disciplinary team consisting of (a) learner support educator(s), psychologists, speech-language therapists/audiologists and occupational therapists. A need for a permanent nurse on the staff was expressed.

6.4 Inclusive education

One respondent commented: *“The whole system is not tailored for inclusive education and does not have real understanding of learners with intellectual impairments and it needs [sic]. No class assistants are available and teachers have to struggle to cope with so many challenges”.*



7. DISABILITY SUPPORT GROUPS / ORGANISATIONS

7.1 Supporting the needs of young children with delays/disabilities and their families

“We have been able to assist some families for free and the services to all families have been highly subsidised through fund raising from our side. In the current economic climate this is becoming increasingly difficult.”

According to the respondents, parents/caregivers require practical training in managing the type of disability the child has, including challenges in terms of behaviour, communication and/or toileting where applicable. For example, in families where hearing impairments are present, sign language training is needed since deaf or hearing-impaired people gain access to information by means of sign language.

A key function of support groups and organisations is the dissemination of relevant information to their members.

Emotional support to parents and caregivers is also important, especially during the adjustment phase after the identification of a disability. This can include facilitating recreational activities for members.

7.2 Useful resources

In general the following media are used by groups: handouts from training/upskill sessions, publications on relevant disabilities and related topics, information on social media and links to websites.

Pamphlets, brochures and posters that are translated in sign language are a very useful resource for persons who are deaf or have a hearing impairment. Furthermore, the translation of national documents into Namibian Sign Language, and the training of more sign language interpreters will make a significant difference in the availability of resources.

Families of children with disabilities will benefit from self-empowerment training, for example, self-care and income generation. The provision of online training will enhance the empowerment of parents/caregivers.

Families with children with ASD will benefit greatly from information on managing associated behaviour and sensory issues.

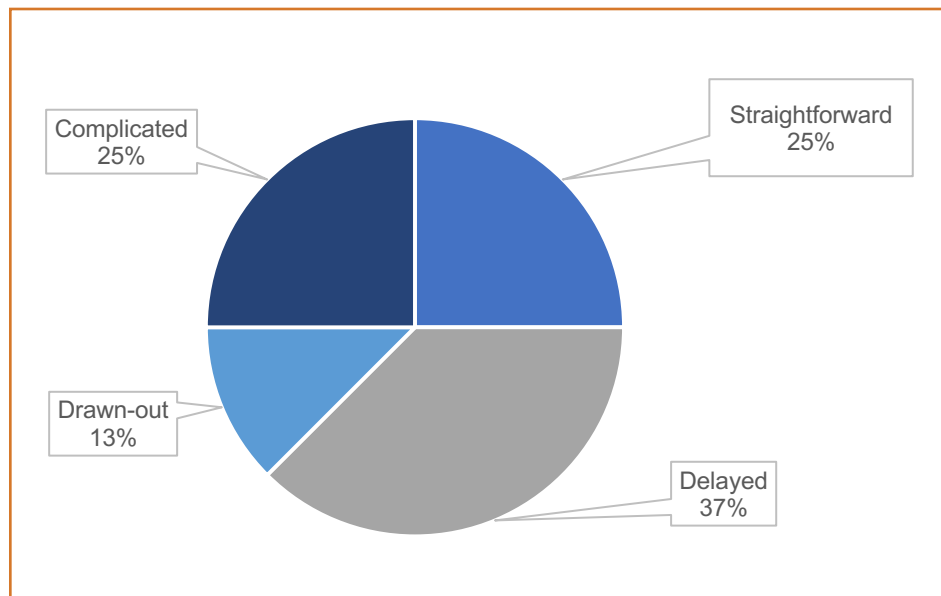
7.3 Training

Of the eight groups/organisations surveyed, 6 of them provide training to their members. Therapists and specialists related to the field of disability (e.g. ASD, CP) are involved. Training in sign language interpretation is an example of these groups' involvement in facilitating optimal participation of their members. Specific training modules are utilised by three of these support groups on the following broad themes: hearing impairment and loss, autism, learning disorders, communication, language development and play/ art therapy.

7.4 Identification of delays/ disability

Figure 1 shows the general experience of the process of identifying delays or disabilities.

Figure 1: General experience of the process of identifying delays or disabilities



More than one professional is generally involved in the identification process. The following disciplines are regarded to be key role players during identification of atypical development: speech-language therapy, audiology,¹⁹ ENT specialist, occupational therapy, educational psychology, education, paediatrics, psychiatry, physiotherapy, social work, nursing, and medical practice.

7.5 Pre-school to Grade 1 transition

A specialised early intervention programme (pre-school and day care centre) is functional for young deaf children in Windhoek. One respondent stated that prioritising ECD centre access and attendance for deaf pre-schoolers and their teachers should be supported in addressing their unique needs in order to establish a sound foundation for this group of learners before entering Grade 1. Early registration of young deaf children on a primary health care database means that their early learning track could be monitored to prevent delayed or absence of school enrolment.

7.6 Intervention

Organisations/support groups offer member education and training as an intervention service. Obviously different limitations require different forms of intervention. For example, (non-verbal) children with ASD and children with hearing impairments have dissimilar communication needs and the latter will be addressed accordingly. The groups also refer members to the appropriate therapists – most relevant of which being the speech-language therapist and occupational therapist.

One respondent commented, “[t]he number of cases coming in, exceed our capacity and it is highest time to expand to be able to continue and improve our services”. The following suggestions emerged with a view to improving intervention services from their perspective:

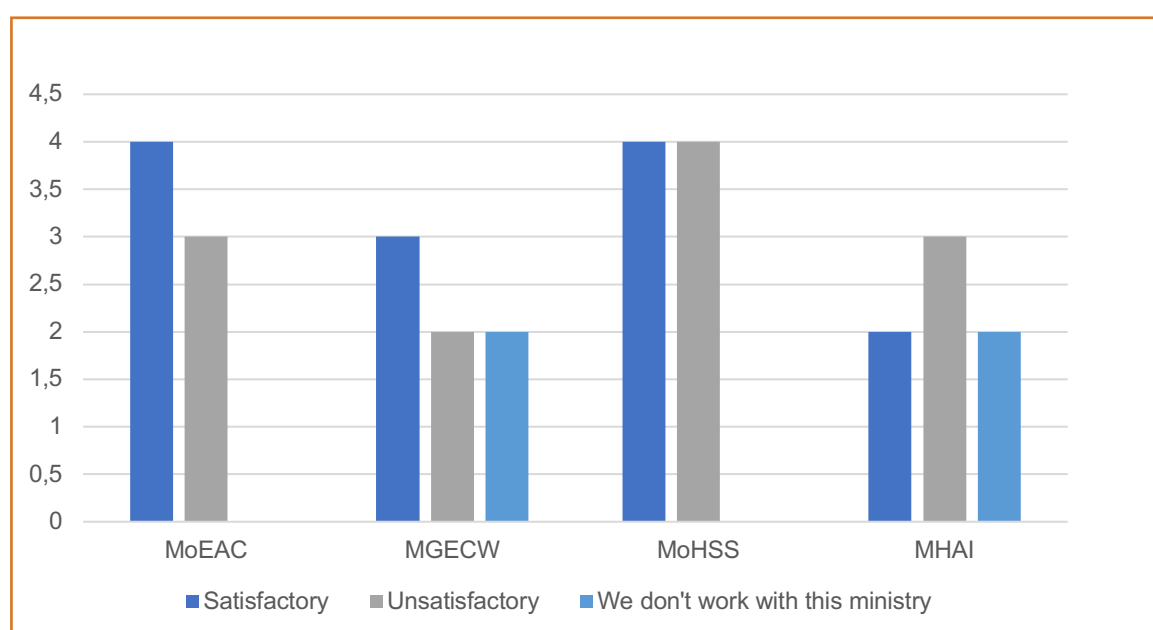
- appointment of staff at regional clinics and hospitals to provide intervention or decentralised (audiology) services
- specialised training of appointed public sector staff
- raising awareness on the importance of early intervention, in rural areas in particular
- home visits by EIEI specialists for earlier identification, monitoring caregiving and providing guidance and support
- access to basic sign language by role models who are deaf/ ECD programs/regular treatment if applicable
- availability of caregiving services for identified children with specialised needs
- social grants
- empowerment of the children and their families: social skills/ life skills/technical training
- education tailored according to the specific needs of children with learning difficulties.

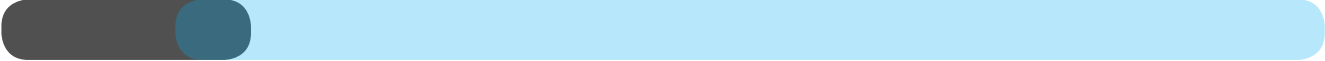
Another respondent added that universities should encourage students to enrol in fields of study that “*help children that are left out ... all special needs children in Namibia*”.

7.7 Ministerial Collaboration

The collaboration between the participating support groups / organisations and the relevant ministries vary in terms of expectation.

Figure 2: How do you rate your working relationship with the following Ministries?





Collaboration will be increased by:

- stakeholder transparency and integrity
- timely communication of reliable information
- willingness of Ministries to embark on partnerships/project cooperation/coordination of service rendering between public and private sector/structuring MoU (Memorandum of Understanding) to formalise a working relationship
- public sector stakeholders attending specialised training²⁰
- increased subsidies for assistive devices / MoEAC sponsoring unaffordable educational resources
- government-subsidised remuneration of specialised qualified key staff members
- addressing inadequate collaboration on inter-ministerial level/aligning budget allocations for the ministries concerned
- revising NIED resources – online and published material – and making them accessible to everyone.

7.8 Private sector collaboration

Many of the participating support groups/organisations stressed the importance of working together with therapists in private practice, to be able to render services to their members. They also link up with other community organisations and support groups, including: Autism Namibia, CLaSH, Okanti Foundation, Down Syndrome Namibia, Disability United Network, World Federation of the Deaf, National Disability Council, National Federation of Persons with Disabilities in Namibia and the UN. Side-by-Side ECD centre, Dagbreek and Môreson School and UNAM were cited as educational institutions.

8. HEALTH PROFESSIONALS

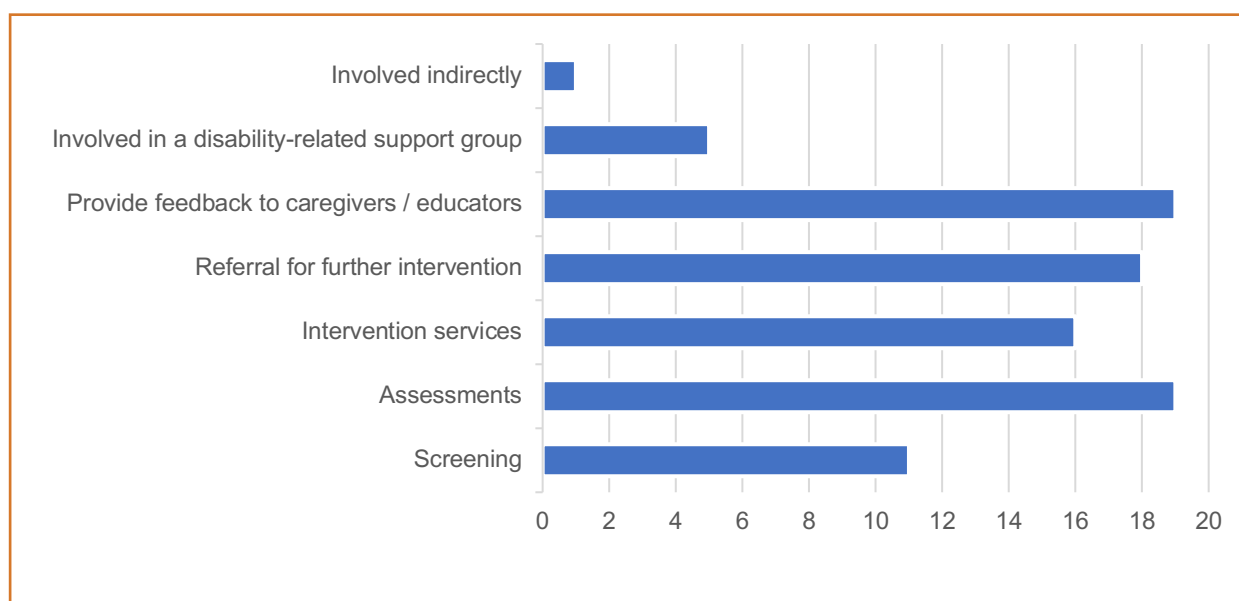
8.1 Quality of professional services

The majority of participating health professionals were trained at tertiary institutions in South Africa, and all of them are registered at the Health Professions Council of Namibia (HPCNA) and some additionally with the Health Professions Council of South Africa (HPCSA). Their respective experience in their field of expertise ranges between nine and 30 years. All respondents have attended additional courses related to their field of disability, quite likely as part of their continuous professional development.

There is a commitment to a basic standard of service delivery. The expertise of some health care providers working in private practice are more accessible to clients as they also travel to their clients or render services at health facilities. Furthermore, their practice fee structure includes reduced/subsidised rates as well as pro bono work – whether at the practice, health facility or as part of an outreach programme. Some participants are affiliated with disability organisations and/or involved with support groups.

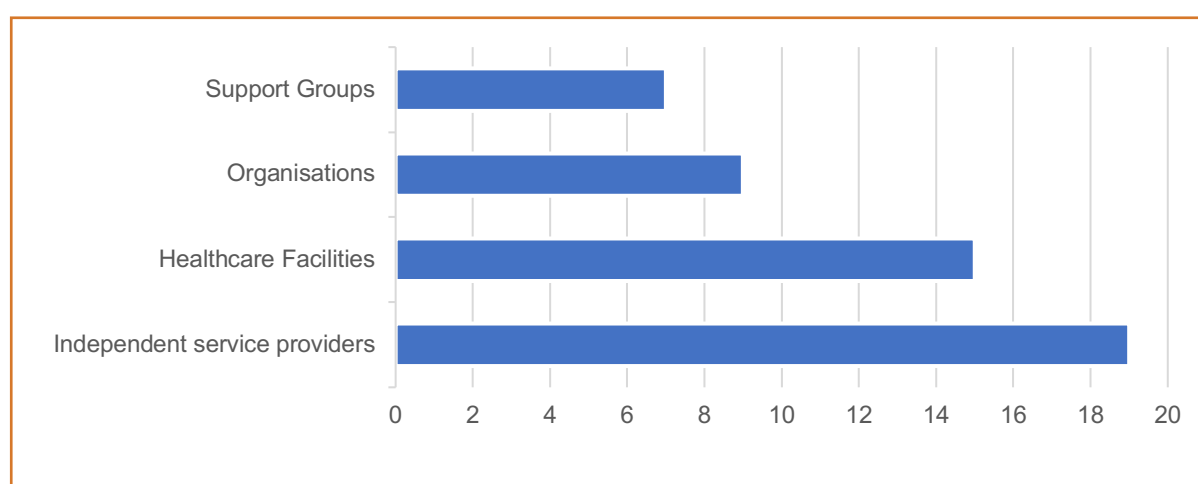
8.2 Current identification and intervention system

Figure 3: Service provider involvement with developmentally vulnerable children



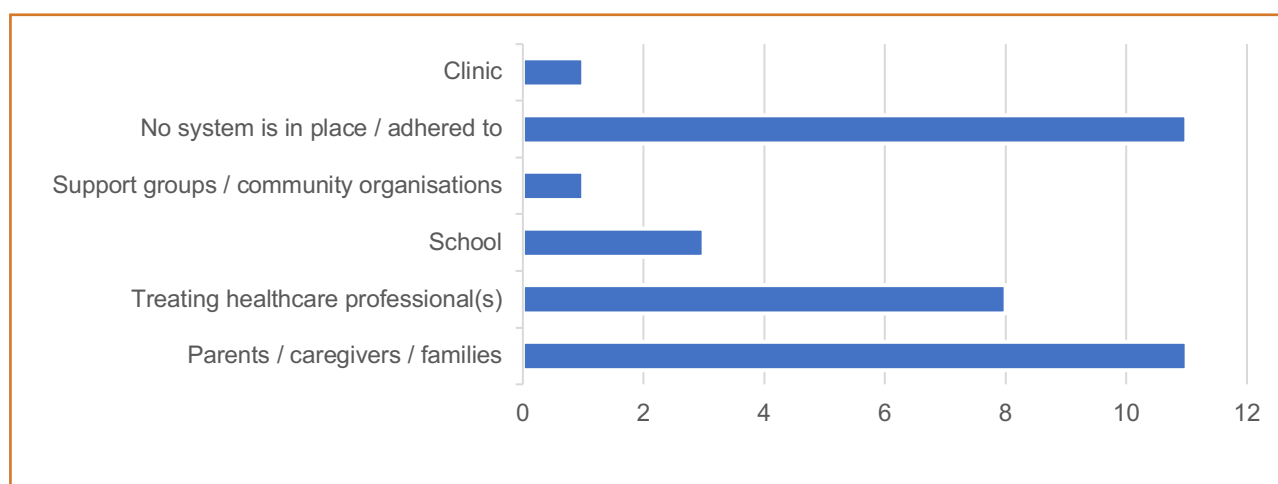
The professional activities described by the respondents working with young children with developmental delays and disabilities, form part of a multi-disciplinary system. When a screening or assessment gives rise to more concern, the child will be referred to another health professional for (further) assessment. Referral to independent service providers is a frequent option.

Figure 4: Who do you refer clients with developmental delays and/or disabilities to?



Depending on the specific circumstances of clients, the service provider will be more or less involved in making arrangements related to the referral. An evaluation report or referral letter must accompany the child after the service provider has made contact with the professional she/he is referring to.

Figure 5: Stakeholders responsible for monitoring at-risk young children



The respondents deliver therapeutic interventions in their respective fields of expertise and give feedback to parents and/or caregivers.

For most respondents the child's Health Passport serves as an important source of information. This document is used to access information pertaining to the child's:

- birth/medical/trauma/symptom history
- history of visits to other health care professionals
- previous tests conducted
- diagnosis (current/previous), and
- chronic medication.

The respondents mentioned the following with regards to improving the functionality of the Health Passport when utilised:

- Health care practitioners should write legibly
- Information provided on tests and treatment should be sufficiently detailed and explained
- Professionals should be able to alert one another to limiting/ challenging circumstances that have relevance to service delivery.

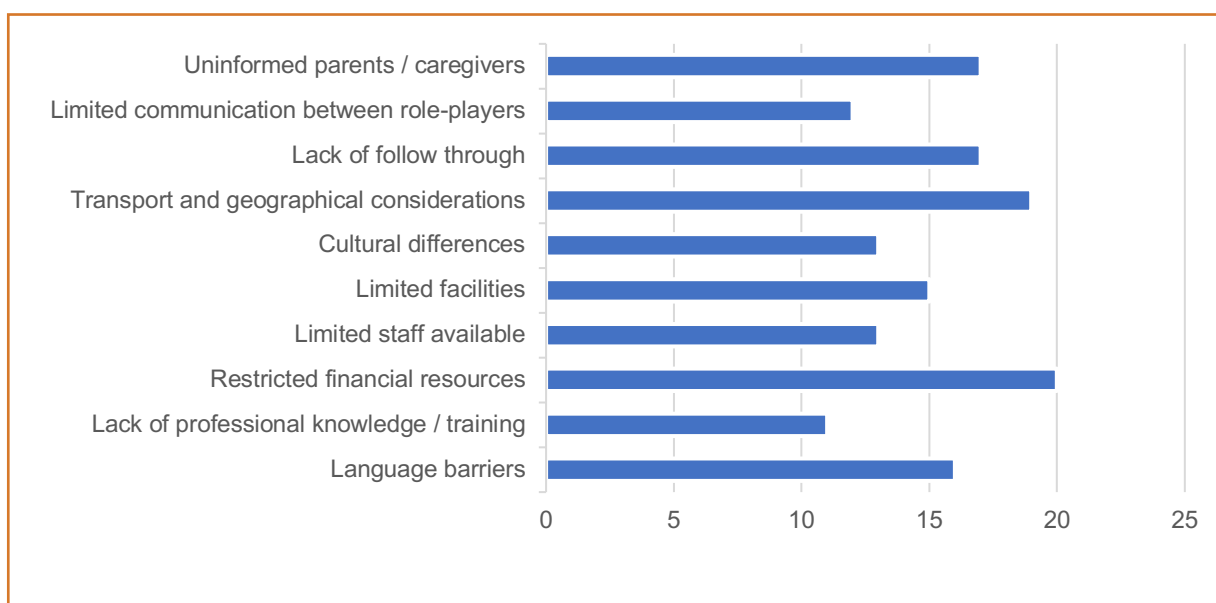
It was also suggested that the data in the Health Passport should also be captured on an electronic database. The results of lab tests will be more readily available and duplication of tests will subsequently be avoided.

The following factors were identified as contributing to early identification of delays and disabilities, and effective intervention:

- birth registration at hospitals
- awareness raising campaigns
- early referral by primary health care practitioners
- flagging of identified developmental risks/ delays
- parental education, including on the services their child might/ will need
- information dissemination by support groups and disability organisations to parents / caregivers
- suitably qualified therapists and teachers
- health care professionals trained in managing disabilities.

Respondents selected factors that they experienced as hindering early identification of delays and disabilities, and effective intervention:

Figure 6: Barriers faced in providing EIEI services



Additional barriers to effective service delivery at an early stage were mentioned, as follows:

- insufficient information dissemination by service providers and media
- misdiagnosis by medical practitioner
- ignorance on the powerful effect of early intervention
- lack of access to required services/ unavailability of occupational therapists and physiotherapists at state hospitals/ insufficient dedicated facilities with appropriately trained staff
- no medication and/or mobility aids available for prescription.

To ensure optimal service delivery the following aspects should be addressed:

- Awareness campaigns
- Adequately qualified and trained health care professionals should be available at health care facilities in every region
- The three key therapy fields – occupational therapy, speech-language therapy and physiotherapy – should be employed at the state hospitals
- Funding for procurement of assistive aids should be prioritised²¹
- The private and public sector should improve collaboration
- Parent/ caregiver training.

8.3 Professional instruments

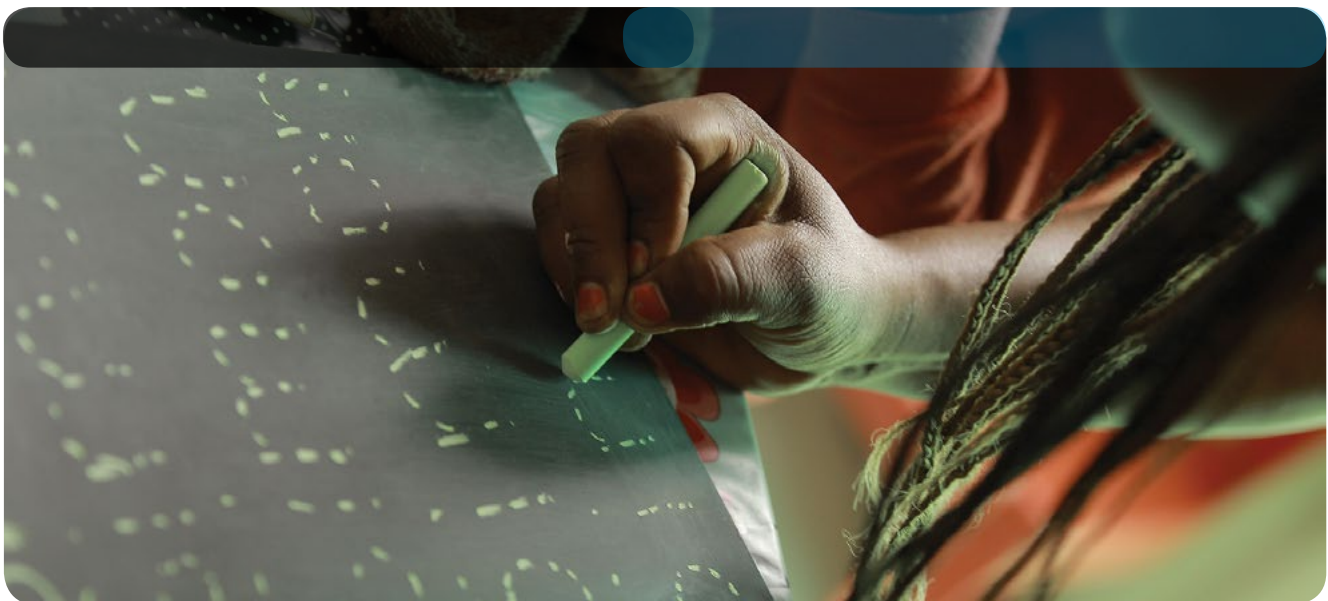
Checklists, online assessment tools, various developmental/medical (Health Passport)/ progress records and observations are utilised for assessment.

Academic publications on relevant research and/or academic lectures are also employed for identification. Diagnostic criteria are applied by some of the respondents, as well as standardised assessment measures (tests). Assessment procedures are used for identification of delays and/or disabilities, but also to monitor the child's progress in therapy.

Professionals encounter difficulties in rendering a basic standard of assessment as a result of:

- unavailability of instruments
- the cost of standardised tests
- insufficient training, and
- checklists/tests that are not standardised for the culturally (including linguistically) diverse Namibian population.

Most respondents are unfamiliar with the ICF system that was developed by the WHO to describe limitations related to delays/disabilities and facilitate optimal functionality.

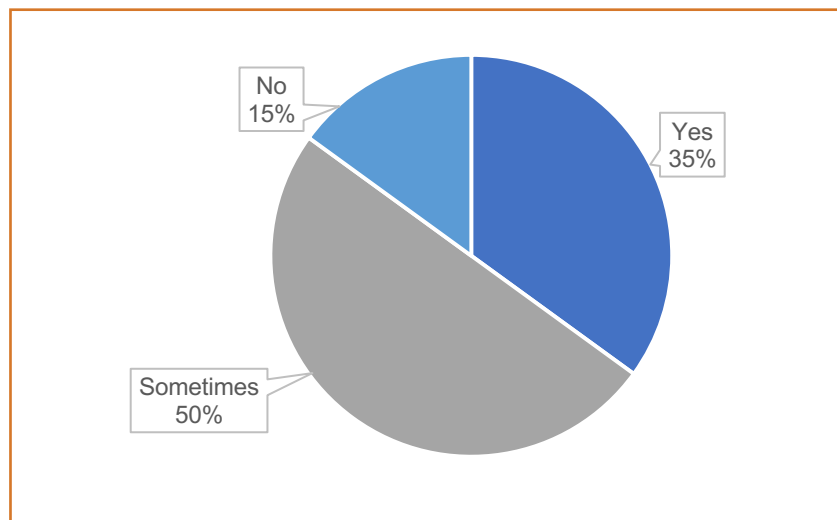


Child practicing hand coordination by writing

8.4 Multi-disciplinary approach

While participants clearly describe their role as part of a multi-disciplinary system (paras 7.3 and 9.2), they do not necessarily function within a multi-disciplinary team to address the issues of delays/ disability:

Figure 7: Do you currently work in a multi-disciplinary team?



8.5 Disability discourse

The attitude of professionals working in the field of disability is generally positive to neutral. For example, to ensure follow-through a child may be kept at the hospital for wheelchair measurements instead of letting the child go home, running the risk that the parent will not bring the child back.

Some respondents mentioned that the traditions of some cultural groups in Namibia do not favour the wellbeing of children with developmental delays/disabilities:

- Non-verbal or non-communicative children are stereotyped as “stupid” and subsequently excluded from groups
- *“One mother was refused to rent a house (shack) because of her disabled child”*
- Epilepsy is stigmatised in communities
- *“Some Namibian cultures hide their disabled children because they are considered to be cursed. Some parents do not care for their disabled children as they see them as a burden and a punishment and because they will not be able to care for them once they are old.”*

9. CHILDREN'S RIGHTS PERSPECTIVE

The international and regional legal instruments ratified by Namibia should guide the theory of change:

- Convention on the Rights of Persons with Disabilities (CRPD)
- United Nations Convention on the Rights of the Child (UNCRC)
- African Charter on the Rights and Welfare of the Child.

One focus group member (Section 2) commented, "*The Rights of Persons with Disabilities is just being ignored. Go back to the basics*".

9.1 Confidentiality

Various stakeholders commented on the issue of confidentiality, particularly the information contained in the Health Passport. In some cases, medical staff are not sufficiently meticulous in their keeping of records. Alternatively, the right of privacy of parents and children should also be respected.²²

9.2 Birth registration

There have been active campaigns in Namibia to ensure that babies acquire a birth certificate as soon as possible after birth. Birth registration is the responsibility of the state, and is directly connected to a child's right to a name or personal identity (Skelton 2016: 603) and a nationality or legal identity (ibid: 604).

According to one group of social workers, in order to combat child abduction, the guidelines on birth registration state that fathers are not allowed to obtain a birth certificate for a child without the permission of the mother. Mothers can register their babies' births without the father's permission.

The potential vulnerability of children with disabilities (para 10.3) requires a speedy birth registration.²³ A birth certificate is required to apply for a disability grant and/ or when a child has to be removed from and placed in care. When parents do not cooperate in providing information needed for their child's birth registration, social workers are frustrated in exercising their child protection mandate. Social workers advocate for a legal system in which parents are legally compelled to comply with registering the baby's birth as soon as possible and obtaining a birth certificate. This system should also make provision for service providers to apply on behalf of a child in the event of the parents not cooperating.

Some educational institutions require a birth certificate for enrolment, while others will accept a Health Passport or an affidavit as confirmation of registration.

Formal services cannot be rendered to non-Namibian children with delays and disabilities or Namibian children whose parents' identifying particulars cannot be entered, traced and/ or certified by a traditional authority.

9.3 Early identification of developmental delays and disabilities and intervention

Discourse on delayed development and childhood disabilities (paras 5.1.1 and 9.5) underpins the practice of hiding or isolating an infant with delay or disability, or the possibility of neglect or abuse by caregivers. The CRPD encourages disability education by information dissemination, support and intervention services with a view to promoting the best interest of the child within the family system²⁴ as soon as possible.²⁵ These services linked to early identification and intervention can limit or even prevent further disability in some instances (para 5.1.11).²⁶

9.4 Disability grant

Some families of children with disabilities have the right to social protection by means of financial assistance.²⁷ However, the application form that is presently used for the child disability grant is invalid as none of the questions are age-appropriate for the developmental level (para 4.2). Additionally, the assessment procedure is regarded to be subjective, and as a result an application for a grant will be granted in one region and not in another, or by one medical officer and not another. The criteria to qualify for a disability grant have been claimed to be applied inconsistently – in some regions children with albinism or epilepsy are excluded.

Major concerns include the following:

- It could be argued that the discrepancy between the adult (16+ years) and the child disability grant is discriminatory, ie.: adult (N\$1300) paid by MPESW and child (N\$250) paid by MGECW. Eight Namibian Dollars per day is completely inadequate to meet the developmental needs of children who require facilitation of functional limitations.
- The processing of grant applications by the Office of the President takes extremely long. This is not in the best interest of children who are born into conditions of extreme poverty.

Alternatively, the “temporary disability” category, (para 5.2.1) as in the case of HIV status (for which allowance needs to be made for recovery), should also have relevance for developmental delays and disabilities.

9.5 Geographical accessibility of health services

Large distances to access health and therapeutic facilities have been noted as a significant barrier to early identification and/or intervention (para 4.2.2). The unavailability of services on a regional level has been noted as a gap with regard to service delivery (paras 2.2, 5.2.3 and 9.2). According to the CRPD, services should be made accessible as close as possible to communities.²⁸

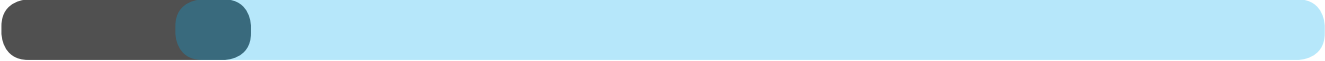
9.6 Procurement of mobility equipment

It is in the best interest of every person with a disability that she/he functions as independently as possible.²⁹ The importance of a child having a mobility aid such as a wheelchair if she/he needs it, was motivated (para 3.2.5). However, many children and their families endure the discomfort of a child’s dependence on others to move around (paras 5.1.12 and 5.1.14), because the procurement of assistive devices is reported to be a long and complicated administrative process.

9.7 Implementation of the Sector Policy on Inclusive Education

There is a strong opinion that the implementation of the Sector Policy on Inclusive Education has been premature because it was not planned sufficiently. *“In practice, a lot of learners were losing out, doing ‘nothing’ and have gone back to their parents.”* The process of implementation is perceived to be excluding learners (paras 4.6 and 7.4) from its essential goal of optimal development of individual potential resulting from participating in a quality education system.³⁰

If the average teacher-learner ratio is 1:45, it will not be possible for a teacher to respond to the varied educational needs of learners including those children with non-neurotypical development, without the following: one or more class assistant, the necessary resources, and the guidance of relevant specialist fields (e.g. occupational therapy, physiotherapy or educational psychology).



The rights of children with ASD, ID and cognitive challenges resulting from neurodevelopmental trauma (e.g. Traumatic Brain Injury (TBI)) to receive a standard of education that includes both support to accommodate their specific social and academic needs and develops their potential to the fullest, seem to be overlooked (para 5.2.3).³¹

Parents and caregivers of children with disabilities and persons with disabilities perceive stakeholders to be disregarding their right of association and their right to be making choices to attend a school that suit their needs, e.g. opting for a “special” class or school rather than an inclusive class or school for the benefits such a class or school may hold in terms of resources and the presence of other learners with disabilities.³² The perception is that teachers in specialised education have empathy and a “heart” for children with varied development and are consequently motivated to create a happy and safe learning environment for learners. They have confidence in the training of these teachers to address learners’ educational needs and manage behaviour associated with various health conditions.

10. PUBLIC POLICY REVISION

The following recommendations pertain to amending political structures on a national/ regional level:

10.1 Establishment of Developmental clinics

The quality of service delivery to very young children with developmental delays or disabilities would be enhanced by the establishment of a developmental clinic in each of the regions. It is suggested that the developmental clinic is linked to the rehabilitation centre due to the benefit this will hold with regards to optimal utilisation of existing infrastructure and resources, as well as professional collaboration.

10.2 Collaboration on inter-ministerial level

The shift of the rehabilitation centres from MoHSS to OVP-DA created administrative and logistical challenges that are directly or indirectly counterproductive to economic and efficient service provision. Budgets are separate, and officials from the different ministries do not collaborate in terms of planning. The rehabilitation officer and liaison officer are not obligated to coordinate their activities. Such working arrangements are not conducive to a team approach.

The preference for community health officers to be active in communities rather than CBR volunteers is motivated on the basis of the former’s level of training and that continuity of services is contractually safeguarded by a job description. However, the CBR volunteers form part of their respective communities and are positioned to develop a relationship of trust with families (para 5.2.1). Furthermore, the Guide to Initiating, Implementing, and Monitoring Community Based Rehabilitation (para 4.1) that was developed for CBR volunteers is an excellent protocol for other ministries to follow to identify developmental delays or disabilities as well.

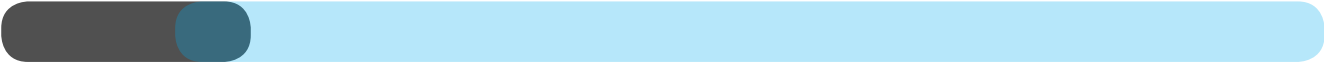
10.3 Staff appointments

The appointment of designated personnel should be prioritised on a regional ministerial level:

MoEAC: speech-language therapy, occupational therapy and educational psychology

A basic multi-disciplinary team should be deployed on regional level, and preferably be housed by a resource school in the region, which will serve as its administrative base.

MoHSS: speech-language therapy, occupational therapy, physiotherapy, orthopaedic technology, nursing and social work



It is preferable that every MoHSS Rehabilitation centre in Namibia should have key therapies on their staff – even if it is on a part-time basis – in order to collaborate as a multi-disciplinary team for the benefit of efficient service delivery. However, even if a single rehabilitation centre per region is set up to approach the relevant needs of the children in multi-disciplinary fashion, the quality of services would already improve. Individualised needs-profiles would guide the courses of therapeutic intervention.

Services rendered geographically closer to the home are less expensive, and more accessible for parents/caregivers to negotiate.

10.4 Strengthening ECD centres

The significance of pre-schoolers, but particularly also young children with developmental delays or disabilities, attending ECD centres should be advanced. Apart from the importance of centre registration, the status of educarers should be evaluated as well. Two relevant factors are level of training and remuneration.

Moreover, consideration should be given to the transfer of the ECD centres, similar to Pre-primary Education, from MGECW to MoEAC. This transfer holds potential for the optimal utilisation of existing human capacity and the application of the inclusive education policy to be synchronised among all developmental phases. Such transfer will particularly benefit very young children with delays and disabilities. For example, the stakeholders will get access to the expertise of DATS and the resources of NIED. The section on Readiness Skills in the Learning Support Teacher's Manual (MoEAC 2014) (para 4.6) specifically comes to mind.

10.5 Disability grant applications

There are two aspects that require investigation concerning child disability grants. Currently, applications are approved or disapproved on the basis of invalid information, subjectively evaluated by state medical officers (para 4.3). Furthermore, it is expected of social workers to make clinical judgements that may or may not fall within their area of expertise (para 4.4).

Secondly, the disparity between the allowance amount for adults with disabilities and the amount for children with disabilities has to be reevaluated (para 10.4). It is argued that the amount is not only very low, but also that "fair discrimination" cannot be applied on the basis of age.

10.6 Procurement of assistive devices

The policy on the procurement of a range of assistive devices required by children with disabilities should be revised. Allocation from the procurement budget should be prioritised and secured. Fast-tracking of an administrative system will not only gain "(developmental) time" for the young children concerned, but also heighten their independence and consequently "buy time" for their families and caregivers.

The range covers mobility equipment such as buggies, wheelchairs, walking frames, orthopaedic shoes or white sticks; devices facilitating sensory limitations such as spectacles, hearing aids and FM systems and augmentative and alternative communication (AAC) aids, for example, braille typewriters, visual sign boards and computer technology.

11. INTEGRATED EIEI SYSTEM

11.1 Referral system

Utilising a multi-disciplinary approach to address developmental delays and disabilities, is respectful of the developing child as a “whole” human being. Various fields of knowledge are converged to gain a holistic understanding of the child’s developmental challenge and to facilitate assistance to her/him and the family accordingly. A powerful advantage of this approach is that, when professionals collaborate, the possibility that parents/ caregivers are confused by different sources of information is minimised.

The basic multi-disciplinary team consists of the following professional fields: speech-language therapy, occupational therapy, psychology, and physiotherapy. Other specialisation fields are involved depending on individualised needs created by the nature and severity of the disability.

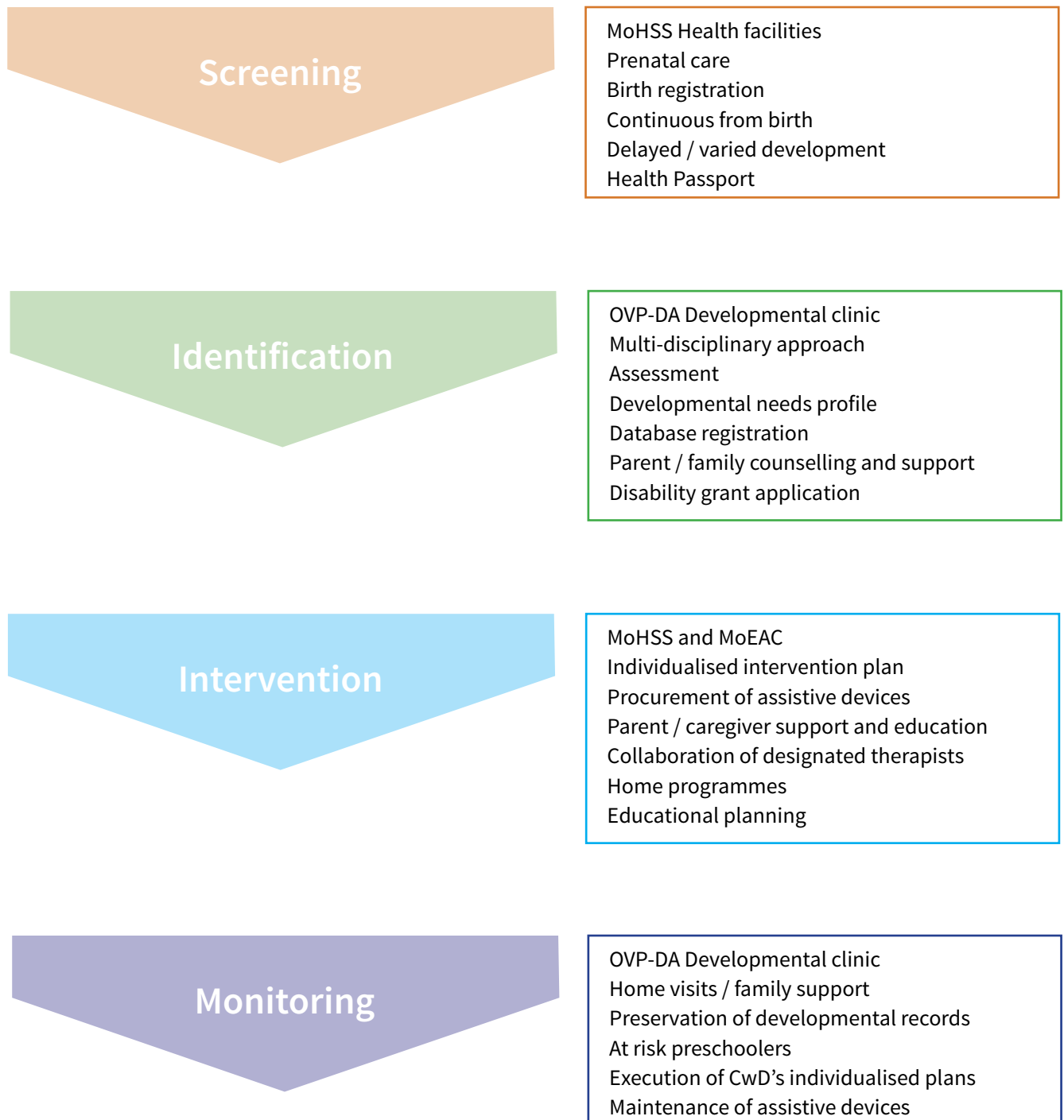
Various factors determine what route referral will take, and which stakeholders will be involved during the process. For example, a physical disability as a consequence of an illness is expected to require a straightforward referral to the rehabilitation clinic. However, the specialist fields to be convened in order to assist a young child with cerebral palsy is related to the neurological impact that needs to be addressed. Children with CP have different needs at different times during their development which implies that service-rendering will be continuous. Multiple disabilities will most likely require the expertise of various therapists. In Table 1, therapists and specialist fields generally associated with a selection of disabilities are provided.

Table 1: Selection of disabilities and involvement of specialist fields/therapies

| | Occupational therapist | Orthopaedic technician | Physio-therapist | Psychologist | Speech-language therapist | SPECIALIST |
|--------------------------------|------------------------|------------------------|------------------|--------------|---------------------------|--|
| Autism Spectrum Disorder (ASD) | ✓ | | | ✓ | ✓ | Paediatrician Psychiatrist |
| Cerebral Palsy (CP) | ✓ | ✓ | ✓ | ✓ | ✓ | Orthopaedic surgeon |
| Cleft lip / palate | | | | | ✓ | Plastic surgeon Prosthodontist |
| Club foot | | ✓ | ✓ | | | Orthopaedic surgeon |
| Hearing impairments | | | | | ✓ | ENT specialist Audiologist Hearing acoustician |
| Intellectual Disability (ID) | ✓ | | | ✓ | | |
| Visual impairments | ✓ | | | | | Ophthalmologist Optometrist |

11.2 Prototype

The following model for an integrated EIEI system is proposed:





12. TRAINING MANUAL

12.1 Guideline

Two themes recurred during the information breakdown process:

- Parents and caregivers require information to be empowered. Education and guidance will not only strengthen their ability to fulfil the needs of their own pre-schooler, but will also allow their active participation in the child's therapeutic process
- Stakeholders also need (advanced) training in order to develop their capacity for service delivery
- Parent/ caregiver modules will be an adapted and simplified version of the contents of the training materials developed for professional role players.

12.2 Contents of Training Manual

The main themes for training are:

- The rights of children with disabilities
- Early childhood development
- The International Classification of Functioning, Disability and Health (ICF) system
- Developmental delays and disabilities
- The neurodevelopmental disabilities
- Early identification and Early intervention protocol
- Neurocognitive development: information processing
- Mediated Learning Experience (MLE)
- Inclusive education.

12.3 Resources

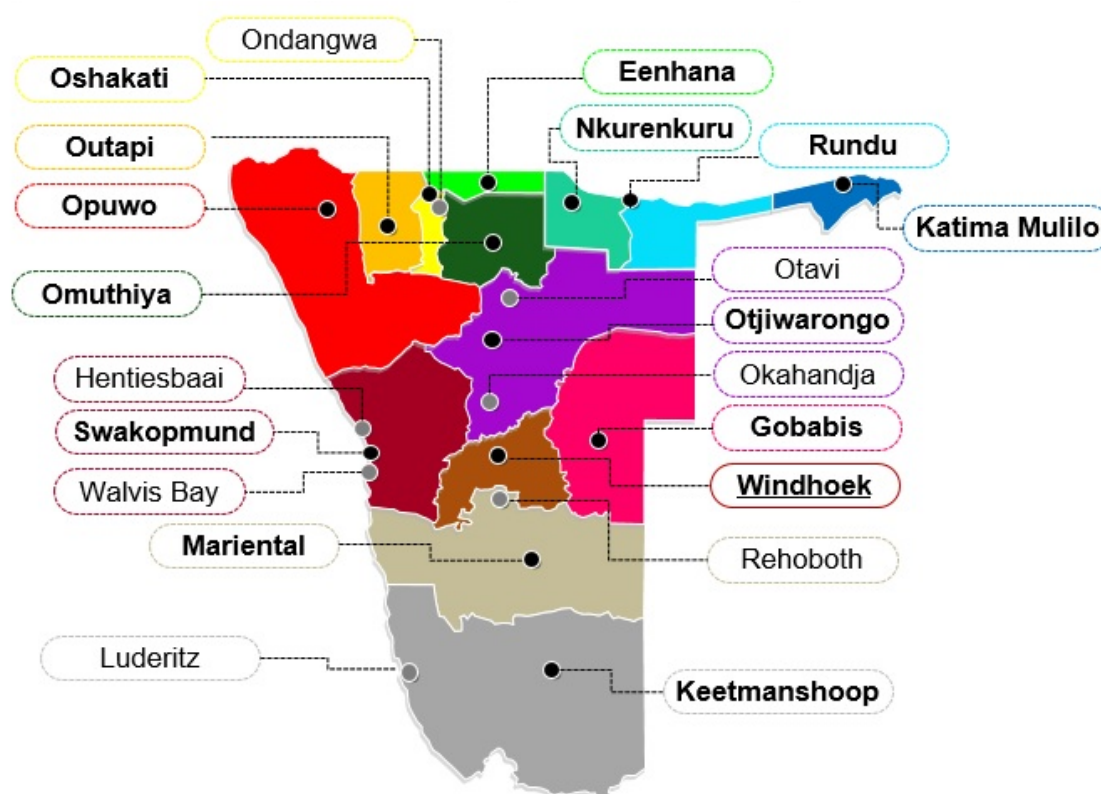
The manual will include a section on resources. Details on additional material that can be used for education and training, and lists for further reading. A directory of therapists, support groups and disability organisations will also be provided to assist stakeholders when referring children.

- American Psychiatric Association (APA). 2013. Diagnostic and Statistical Manual of Mental Disorders. Fifth Edition (DSM-5). Arlington, VA: APA.
- Mahery, P. 2009. The United Nations Convention on the Rights of the Child: Maintaining its Value in International and South African Law. In Boezaart, T. (Ed.) Child Law in South Africa. Cape Town: JUTA.
- Ministry of Health and Social Services, Namibia. wd. Guide to Initiating, Implementing, and Monitoring Community Based Rehabilitation. Ministry, Directorate: Social Welfare Services.
- Ministry of Education, Namibia. 2014. Learning Support Resource Book. Second Edition. Okahandja: National Institute for Educational Development (NIED).
- Ministry of Education, Namibia. 2014. Learning Support Teachers' Manual. Second Edition. Okahandja: National Institute for Educational Development (NIED).
- Moore, S.A., Melchior, L. & Davis, J.M. 2008. 'Me and the 5 P's': Negotiating Rights-Based Critical Disabilities Studies and Social Inclusion. International Journal of Children's Rights 16: 249-262.
- Skelton, A. 2016. Children. In Currie, I. & De Waal, J. (Eds.) The Bill of Rights Handbook. Sixth Edition. Cape Town: JUTA.
- Viljoen, F. 2009. The African Charter on the Rights and Welfare of the Child. In Boezaart, T. (Ed.) Child Law in South Africa. Cape Town: JUTA.
- Werning, R., Artiles, A.J., Engelbrecht, P., Hummel, M., Caballeros, M. & Rothe, A. 2016. Keeping the promise? Contextualizing inclusive education in developing countries. Bad Heilbrunn: Verlag Julius Klinkhardt.
- https://www.pedocs.de/volltexte/2016/12353/pdf/Werning_et_al_2016_Keeping_the_promise.pdf
- World Health Organization. 2001. International Classification of Functioning, Disability and Health (ICF). Geneva: WHO.
- World Health Organization. 2007. International Classification of Functioning, Disability and Health: Children & Youth version (ICF-CY). Geneva: WHO.

SCHEDULE OF IN-COUNTRY RESEARCH ACTIVITIES FROM 20 JANUARY TO 07 FEBRUARY 2020

The map indicates the regional capitals, significant towns and the fieldwork sites visited during January-February 2020. The research activities are described in the table that follows.

Namibian Regional Capitals and Significant Towns



| DATE | REGIONAL CAPITAL/ TOWN | RESEARCH SITE | ACTIVITY |
|----------|--------------------------|--|--|
| 20/01/20 | Katima Mulilo, ZAMBEZI | Katima Mulilo Hospital | Focus group - 10 participants |
| 21/01/20 | Rundu, KAVANGO EAST | Sauyemwa Centre for the Visually Impaired | Visit |
| 22/01/20 | | OVP-DA Regional office | Focus group - 13 participants |
| | | Rehabilitation Centre, Rundu Hospital | Visit and interview with occupational therapist and orthopaedic technologist |
| | | MoEAC Regional office | Focus group - 06 participants |
| 23/01/20 | | Specialised Unit, Dr Romanus Kampungu Secondary School | Visit |
| | Nkurenkuru, KAVANGO WEST | OVP-DA Regional office | Interview with two representatives |

| DATE | REGIONAL CAPITAL/ TOWN | RESEARCH SITE | ACTIVITY |
|----------|--|---|---|
| 24/01/20 | Eenhana, OHANGWENA | ECD Centre, Ouholamo | Observation |
| | | Rehabilitation Centre, Eenhana Hospital | Visit |
| | | MoHSS Regional office | Focus group - 12 participants |
| | | MoEAC Regional office | Focus group - 12 participants |
| | | MGECEW Regional office | Interview with two social workers and snr administrative officer |
| 27/01/20 | Opuwo, KUNENE | Rehabilitation Centre, Opuwo Hospital | Visit - Interview with snr liaison officer and community health worker |
| | | Opuwo Hospital | Focus group - 15 participants |
| | | Nils Centre for the Deaf | Visit |
| | | MGECEW Regional office | Interview with two social workers |
| 28/01/20 | Oshifu, OMUSATI | Nakayale Private Academy | Enquiry |
| 29/01/20 | Omuthiya, OSHIKOTO Ondangwa, OSHIKOTO Oshakati, OSHANA | Oshakati Hospital | Focus group - 41 participants |
| | | Dr Frans Aupa Indongo Special Care Centre | Visit |
| 30/01/20 | Ondangwa, OSHIKOTO | Circle of Hope Private School | Visit - Interview with principal Interview with parent of pupil with neurodevelopmental disability Interview with parents of prospective pre-schooler with delays |
| 31/01/20 | Otjiwarongo, OTJOZONDJUPA | Otjiwarongo Hospital | Focus group - 10 participants |
| | | Rehabilitation Centre, Otjiwarongo Hospital | Visit |
| 03/02/20 | Keetmanshoop //KARAS | //Karas Resource Centre | Focus group - 22 participants |
| | | Step-by-Step ECD centre | Visit - Interview with parent and guardian of two respective children with severe CP |
| | | //Karas Resource Centre | Attendance Parent support group Namibian Association for Children with Disabilities |
| 04/02/20 | Mariental, HARDAP | MoHSS Regional office | Focus group - 17 participants Focus group - 12 participants |
| 05/02/20 | Windhoek, KHOMAS | Physiotherapy Department, Katutura Hospital | Interview with occupational therapist and physiotherapist |
| | | Windhoek Central Hospital | Interview with clinical psychologist |
| 06/02/20 | Gobabis, OMAHEKE | MoHSS Regional office | Interview with liaison officer, physio-therapist and occupational therapist |
| | | MGECEW Regional office | Interview with social workers and administrative officer |
| | | MoEAC Regional office | Interview with school counsellor |
| 07/02/20 | Swakopmund, ERONGO | Stepping Stone Special Education School | Interview with principal |

FIELDWORK PARTICIPANT DETAILS PER REGION

Table 2: Number of participants per region

| REGION | PARTICIPANTS | | |
|---------------------|--------------|-----------|------------|
| | Female | Male | SUBTOTAL |
| Zambezi | 10 | x | 10 |
| Kavango East | 15 | 12 | 27 |
| Kavango West | 02 | x | 02 |
| Ohangwena | 16 | 13 | 29 |
| Kunene | 06 | 17 | 23 |
| Oshana and Oshikoto | 30 | 15 | 45 |
| Otjozondjupa | 07 | 03 | 10 |
| //Kharas | 14 | 10 | 24 |
| Hardap | 23 | 06 | 29 |
| Khomas | 03 | x | 03 |
| Omaheke | 03 | 05 | 08 |
| Erongo | 01 | x | 01 |
| GRAND TOTAL | 130 | 81 | 211 |

Table 3: Participants' level of education

| REGION | LEVEL OF EDUCATION | | | |
|---------------------|--------------------|-----------|------------|-----------|
| | Primary | Secondary | Tertiary | Unknown |
| Zambezi | | 03 | 07 | |
| Kavango East | | 04 | 16 | 07 |
| Kavango West | | 02 | | |
| Ohangwena | | 03 | 25 | 01 |
| Kunene | | 04 | 19 | |
| Oshana and Oshikoto | | 17 | 28 | |
| Otjozondjupa | | 03 | 07 | |
| //Kharas | 07 | 10 | 02 | 05 |
| Hardap | 02 | 13 | 14 | |
| Khomas | | | 03 | |
| Omaheke | | 04 | 04 | |
| Erongo | | | 01 | |
| GRAND TOTAL | 09 | 63 | 126 | 13 |

Table 4: Language distribution of participants

Table 5: Stakeholder capacity of participants

| REGION | LANGUAGE | | | | | | | | | | | |
|---------------------|-----------|---------|--------------------|---------------|-----------|------------|-------------------------|--------------------------|------------|------|-----------------|---------|
| | Afrikaans | English | European Languages | Nama / Damara | Oshiwambo | Otjiherero | Other African languages | Other Namibian languages | RuKwangali | Sign | Silozi / Subiya | Unknown |
| Zambezi | | | 02 | | 01 | | | | | | 06 | 01 |
| Kavango East | | | | | 01 | | 01 | 08 | 10 | | | 07 |
| Kavango West | | | | | | | | | 02 | | | |
| Ohangwena | | 01 | | | 27 | | | | | | | 01 |
| Kunene | | 01 | 01 | | 09 | 11 | | | | | 01 | |
| Oshana and Oshikoto | | 02 | | | 35 | 01 | 06 | | | 01 | | |
| Otjozondjupa | | | | 03 | 04 | 01 | 01 | | | | 01 | |
| //Kharas | 08 | | | 11 | | | | | | | 01 | 04 |
| Hardap | 06 | 03 | | 16 | 03 | 01 | | | | | | |
| Khomas | | 01 | | | 01 | | 01 | | | | | |
| Omaheke | | | | 01 | 01 | 02 | 01 | | 01 | | 02 | |
| Erongo | 01 | | | | | | | | | | | |
| GRAND TOTAL | 15 | 08 | 03 | 31 | 82 | 16 | 10 | 08 | 13 | 01 | 11 | 13 |

| REGION | STAKEHOLDER CAPACITY | | | | | | | |
|---------------------|----------------------|-------------------------|------------|--------------------|---------------------------|---------------------------|--------------------|-----------|
| | Community | Disability Organisation | Ministries | Parent / caregiver | Persons with Disabilities | Private Primary education | Tertiary education | Unknown |
| Zambezi | | | 02 | | 01 | | | |
| Kavango East | | | | | 01 | | 01 | 08 |
| Kavango West | | | | | | | | |
| Ohangwena | | 01 | | | 27 | | | |
| Kunene | | 01 | 01 | | 09 | 11 | | |
| Oshana and Oshikoto | | 02 | | | 35 | 01 | 06 | |
| Otjozondjupa | | | | 03 | 04 | 01 | 01 | |
| //Kharas | 08 | | | 11 | | | | |
| Hardap | 06 | 03 | | 16 | 03 | 01 | | |
| Khomas | | 01 | | | 01 | | 01 | |
| Omaheke | | | | 01 | 01 | 02 | 01 | |
| Erongo | 01 | | | | | | | |
| GRAND TOTAL | 15 | 08 | 03 | 31 | 82 | 16 | 10 | 08 |

Table 6: Ministries represented among participants

| REGION | REPRESENTATION OF MINISTRIES | | | | | |
|---------------------|------------------------------|-----------|-----------|-----------|-----------|-----------|
| | MGECW | MoEAC | MoHSS | MHAI | MoSY | OVP-DA |
| Zambezi | | 03 | | | | 02 |
| Kavango East | 02 | 10 | 02 | | | 01 |
| Kavango West | | 01 | | | | 01 |
| Ohangwena | 03 | 12 | 10 | | | 02 |
| Kunene | 07 | 01 | 10 | | | 05 |
| Oshana and Oshikoto | | 07 | 14 | | | 03 |
| Otjozondjupa | | 01 | 06 | | 01 | 02 |
| //Kharas | | 01 | | | | 01 |
| Hardap | 02 | 08 | 04 | 02 | | 01 |
| Khomas | | | 03 | | | |
| Omaheke | 03 | 02 | 02 | | | 01 |
| Erongo | | | | | | |
| GRAND TOTAL | 17 | 46 | 44 | 02 | 01 | 19 |

Table 7: Distribution of health and education professions among participants

| REGION | HEALTH AND EDUCATION PROFESSIONS | | | | | | | | | | |
|---------------------|----------------------------------|---------|-----------|---------------------|---------|---------------------------|----|------------|----|----------------|----|
| | Audiology / SLT | Educare | Education | Medical practice | Nursing | Orthopaedic Technology | OT | Psychology | PT | Rehabilitation | SW |
| Zambezi | | | 02 | | | | | | 01 | | |
| Kavango East | | | 05 | | | 01 | 01 | | | | 01 |
| Kavango West | | | | | | | | | | | |
| Ohangwena | | | 12 | | 03 | | | | 02 | 01 | 05 |
| Kunene | | | 02 | 01 | 01 | 01 | | | | | 04 |
| Oshana and Oshikoto | | | 11 | | 07 | | 04 | | 01 | | 01 |
| Otjozondjupa | | | | | 01 | | 01 | | | | 01 |
| //Kharas | | | 01 | | | | | | | | |
| Hardap | | 02 | 05 | 02 | 01 | | | | | | 02 |
| Khomas | | | | | | | 01 | 01 | | | |
| Omaheke | | | | | | | 01 | | | | 02 |
| Erongo | | | 01 | | | | | | | | |
| GRAND TOTAL | 00 | 02 | 39 | 03 | 13 | 02 | 08 | 01 | 05 | 01 | 16 |

SUPPORT GROUPS/ DISABILITY ORGANISATIONS

| Services provided in the following languages / communication mediums ³³ | TOTAL |
|--|-------|
| English | 7 |
| Afrikaans | 2 |
| Sign Language | 3 |
| Oshindonga | 1 |
| German | 1 |

Figure 8: Level on which services are rendered

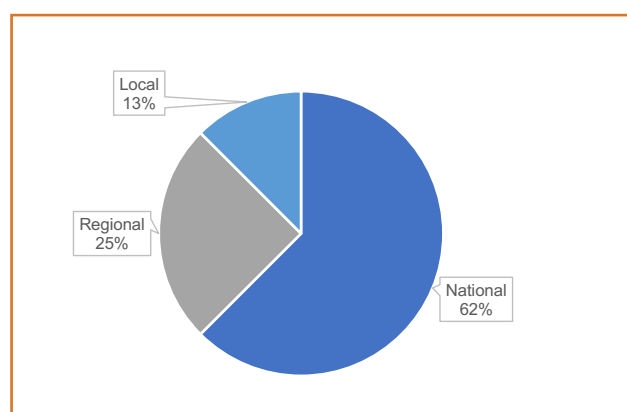
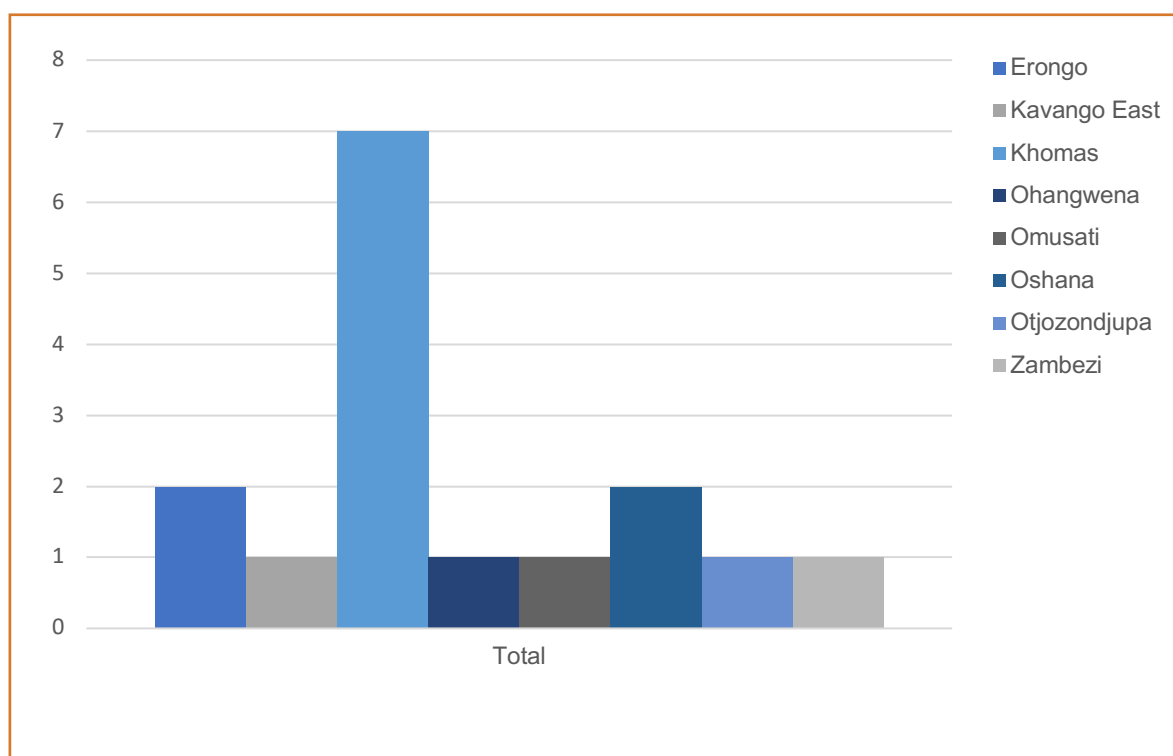
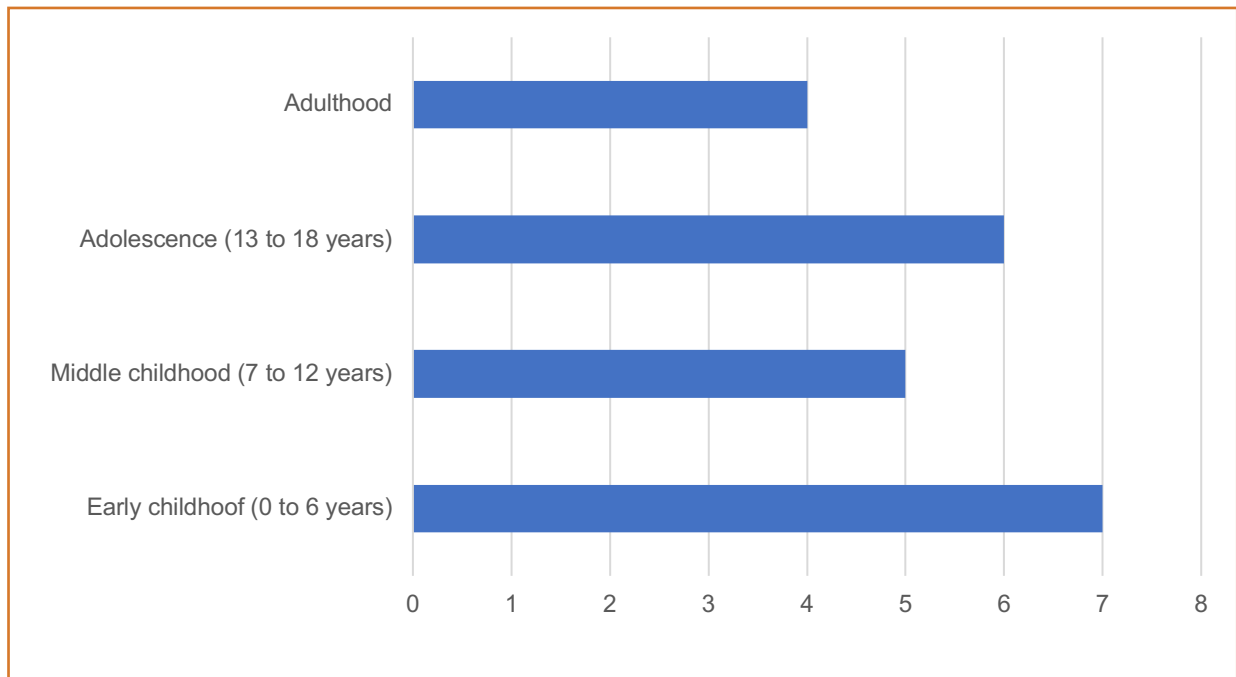


Figure 9: Region(s) in which services are based



Head offices centralised in Windhoek (7 out of 8).

Figure 10: Developmental phases catered to

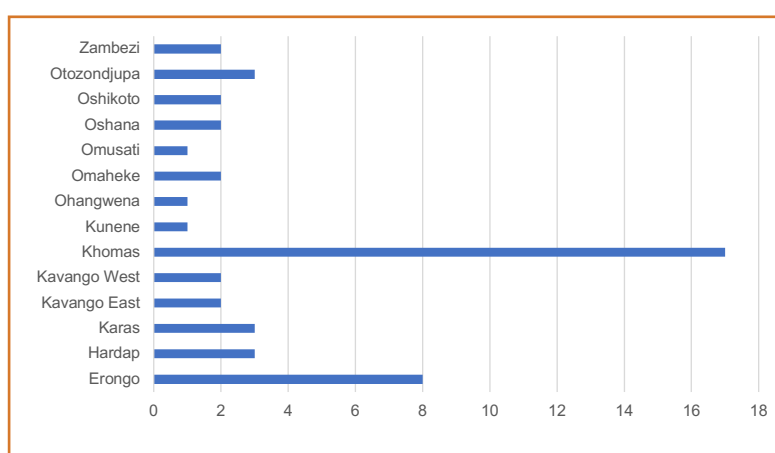


Disability groups represented: children with hearing loss / who are deaf; people with Down Syndrome; mental illness; ASD and communication disorders; various disability groups; children with CP, Dyspraxia, Epilepsy, Dyslexia

PROFESSIONALS

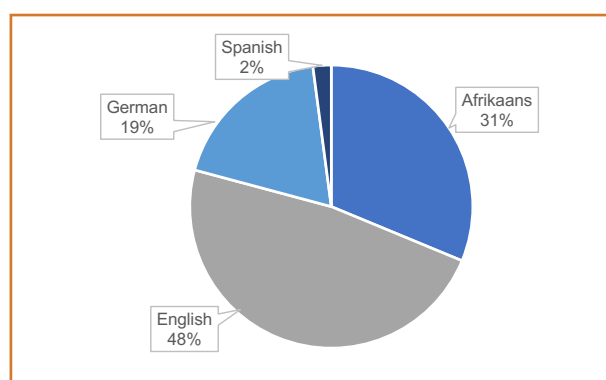
| Specialist Field | TOTAL |
|-------------------------------------|-----------|
| Audiology / Hearing Acoustician | 2 |
| Audiology / Speech-language therapy | 1 |
| Speech-language therapy | 3 |
| Chiropractor | 1 |
| Dietitian | 2 |
| Occupational Therapy | 3 |
| Optometry | 1 |
| Paediatrics | 1 |
| Physiotherapy | 5 |
| Psychology | 4 |
| Total | 23 |

Figure 11: Service distribution per region



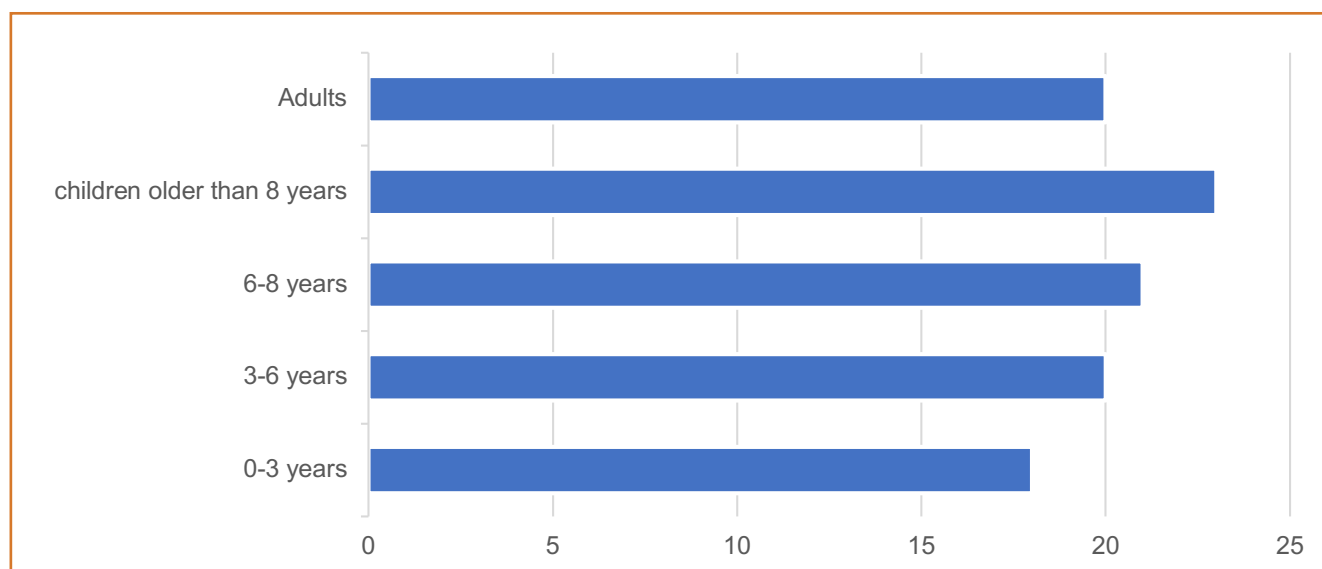
| Fee Structure Utilised | TOTAL |
|---|-------|
| Private rates (including medical scheme rates) | 20 |
| Subsidised services | 3 |
| Pro bono (free) services – including outreach programme | 12 |
| Reduced rate | 8 |

Figure 12: Languages in which services are rendered



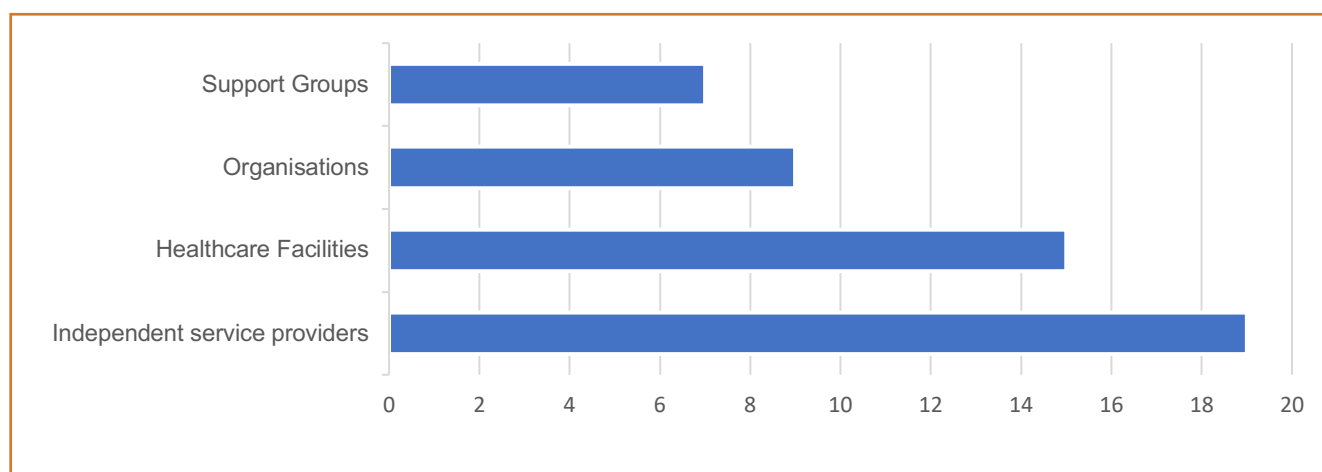
| Do you or your clients travel for consultations? | TOTAL |
|--|-------|
| I only see local clients. | 3 |
| I consult with clients who travel to a state medical facility. | 4 |
| I travel to see my clients. | 9 |
| My clients travel to see me at my practice. | 20 |

Figure 13: Age groups catered to



| Familiarity with the ICF system developed by WHO | TOTAL |
|--|-------|
| I make use of this system. | 3 |
| I'm aware of it. | 6 |
| I'm unfamiliar with it. | 11 |

Figure 14: Who do you refer clients with developmental delays and/or disabilities to?



EARLY IDENTIFICATION OF DISABILITY

Health Worker's Screening Chart

| | months | | | | | | years | |
|---|---|--|---|---|---|---|--|---|
| | 0 | 3 | 6 | 9 | 12 | 18 | 2 | 3 |
| Age | | | | | | | | |
| Large Movements | <p>If the child does not suck properly, or cry at birth, and if Appar Scale is less than 6, it can indicate that he/she may be at risk for developing problems.</p> | <p>Can hold head up when lying on tummy and head firm when sitting.</p> <p>Lies symmetrically, can wiggle and kick with legs and arms.</p> | <p>Can sit using own support.</p> <p>Can roll over.</p> | <p>Starts crawling.</p> <p>Can twist around when sitting.</p> | <p>Walks alone or with one hand held.</p> | <p>Walks well.</p> <p>Squats to play.</p> <p>Runs, but falls often.</p> | <p>Starts climbing and jumps on both feet.</p> <p>Depends on adults for dressing but helps undress himself.</p> | <p>Is able to jump.</p> <p>Can stand on one foot for a short while.</p> |
| Vision and Fine Movements | <p>Can suck well:</p> <ul style="list-style-type: none"> - cheeks are active - lip closure around the nipple. - sucks strongly. | <p>Uses eyes to follow close objects.</p> <p>Can bring hands to mid-line.</p> | <p>Watches, reaches and grasps objects.</p> | <p>Looks for objects put out of sight and picks up small objects.</p> <p>Can transfer toys from hand to hand.</p> | <p>Points to objects in the distance.</p> <p>Picks up things with thumb and one finger.</p> | <p>Enjoys looking at pictures and objects.</p> <p>Can place 1 - 3 objects on top of one another.</p> | <p>Starts scribbling.</p> <p>Puts one object in a bottle at a time.</p> <p>Can feed self.</p> | <p>Can string beads together.</p> <p>Can copy the symbols "0" and "X".</p> |
| Speech, Hearing and Social Interactions | <p>Cries at birth.</p> | <p>Tries to turn head toward sound of voice.</p> <p>Coos and gurgles when talked to.</p> <p>Makes eye contact.</p> | <p>Turns head to sounds and voices.</p> <p>Enjoys babbling.</p> | <p>Listens carefully to voice.</p> <p>Understands the word "No".</p> <p>Makes lots of tuneful babble.</p> <p>Uses voice to get attention.</p> | <p>Understands words and simple instructions.</p> <p>Can say two words.</p> | <p>Understands simple instructions.</p> <p>Uses several recognisable words with gestures.</p> <p>Waves "bye-bye".</p> | <p>Follows two instructions: "Get your cup and bring it."</p> <p>Unable to share, possessive.</p> <p>Uses two or three word sentences eg. "More, water."</p> | <p>Listens to stories and takes turns in simple conversations and games.</p> <p>Uses short sentences.</p> <p>Hears or responds when called from another room.</p> <p>Toilet trained.</p> <p>Can dress self.</p> |



UN Partnership on the Rights of Persons with Disabilities
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¹Does your child have a speech, language or hearing problem?

²Health workers' screening chart (Early identification of disability)

³DSM-5 (APA 2013): Specific Learning Disorder

⁴Treatment and Education of Autistic and Communication related handicapped Children

⁵Association of Children with Speech, Language and Hearing Impairments

⁶Self-care, Learning to communicate, Learning to think, Learning to read, Learning to write, Learning numbers, Learning English as a second language, Learning motor skills, Cognitive skills, Learning Pre-literacy skills, Emotional and social skills

⁷The one passport reflects the maternal family name and surname, and the other the paternal family name and surname.

⁸for example, prolonged labour, jaundice, no crying, premature birth, low Apgar score

⁹The nursing staff use the developmental milestones / guidelines in the Health Passport to do developmental screening of infants:

2-3 weeks- grasp, eye movement, sound and core strength

1 month-sensory awareness, reflexes

Continuous-developmental milestones (p 27)

Under / overnutrition (graphs and p 26)

¹⁰For example, seven days after the first casting for club foot according to the Pontsetti method, the infant has to be back for the next step in the correction process. If she / he does not pitch, the correction process is delayed and consequently extended. It is even possible that the child can have a relapse if the casting is not attended to within time.

¹¹Audiology and speech and language therapy services are limited to Windhoek Central Hospital. Psychiatric / psychological services for this age group are available at the Mental Health Clinic at Windhoek Central Hospital.

¹²If the shoes of the child with club feet are not regularly checked and adjusted according to the growth of the feet, she / he can develop scoliosis. Similarly, unattended CP can result in permanent loss of mobility. Consequently a deformity turns into a disability as a result of inadequate timeous treatment.

¹³Reviewing the report, a steering committee member commented: "This seems hard to believe since CLaSH is the only pre-school for learners with hearing impairment unless they are put in mainstream classes".

¹⁴Augmentative and Alternative Communication

¹⁵An internal locus of control refers to a personal belief that one has control over one's life and can make decisions to that effect. A person with an external locus of control believes that external forces determine outcomes and consequently decision making does not serve much of a purpose.

¹⁶He is a child of six years old who still wears nappies. His mother has to work and she cannot afford an assistant to look after him. She therefore just leaves him at home. There is no one to change his nappies.

¹⁷For example, the mother sells vetkoek for an income. Because she has no one to look after her child with severe CP, he goes with her to her stall. Her son's drooling puts her prospective clients off and they walk past her stall.

¹⁸"I know the schools in Windhoek are good, but I will not allow her to go. If my family can neglect my child, what about those people I don't know?"

¹⁹"with access to a brainstem audiometer"

²⁰"Government ministries should budget for upskilling every year so that their staff can attend workshops and courses when we bring in specialists from South Africa or abroad."

²¹The final comment of a participant: "How is the Ministry of Disability Affairs assisting the disabled in procuring essential resources such as assistive devices needed to function?"

²²CRPD Article 22(2): States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

²³CRPD Article 18(2): Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

²⁴CRPD Article 23(3): States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

²⁵CRPD Article 26(1)(a): these services and programmes (b)egin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths.

²⁶CRPD Article 25(b): Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities among children and older persons.

²⁷CRPD Article 28(2)(c): State parties ... shall take appropriate steps to safeguard and promote the realization of this right, including measures (t)o ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care.

²⁸CRPD Article 25(c): Provide these health services as close as possible to people's own communities, including in rural areas;

CRPD Article 26(1)(b): Services and programmes ... are available to persons with disabilities as close as possible to their own communities, including in rural areas.

²⁹CRPD Article 20:

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by

- (a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- (b) Facilitating access by person with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;

³⁰CRPD Article 24:

1. State Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

- (a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- (b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- (c) Enabling persons with disabilities to participate effectively in a free society.

³¹CRPD Article 24(2)(e): Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

³²UNCRC Article 15 Right of association, African Charter Article VIII Freedom of Association

³³"Please note that this question is not clear, plus the listed languages have not been researched well - linguistically!"-comment by a respondent

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