

Access to Justice

for Persons with Down
syndrome and other
intellectual disabilities
in South Africa



An information booklet for DSSA members, parents and caregivers on Access to justice. Developed By Down Syndrome South Africa and Sponsored by the New Zealand High Commission. ©2023

“The new South Africa should be accessible and open to everyone. We must see that we remove the obstacles...Only then will the rights of persons with disabilities to equal opportunities become a reality”

Nelson Rolihlahla Mandela, 1995

Acknowledgements

Down Syndrome South Africa (DSSA), is fortunate to have a network of talented, committed people who were prepared to join hands in this extremely important project and contribute to making a difference in the lives of persons with intellectual disabilities.

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The writer

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All life is a gift, and we are all lucky to share in it.

The "Lucky Few" symbol has a positive message of love and inclusion.

The symbol exemplifies the fact that Down Syndrome families view themselves as lucky.

The number three is symbolic of Down Syndrome, also called Trisomy 21, in which children are born with three copies of the 21st chromosome.

Furthermore, the arrows symbolize moving ahead, despite initial difficulty, "we can only launch forward after we have been pulled back and stretched."



Foreword

Since 1994 the South African government has introduced various policies and legislative frameworks to mainstream disability into all sectors of society. However good the intention, poor implementation, and lack of adequate resourcing of these reforms have unfortunately not evolved progressively to protect the rights of persons with disabilities in South Africa.

In 2019 and 2020, the Down Syndrome community was shocked by three noteworthy events that shaped the development of this resource booklet.

With the outbreak of COVID-19 we saw an increase in violence against children with disabilities due to strict lockdown protocol, confined spaces, and elevated levels of uncertainty, which left many children and adults with disabilities in a vulnerable space. This motivated us to question the state of justice for persons with intellectual disabilities, specifically Down Syndrome in South Africa.

In August 2019, a 12-year-old boy with Down Syndrome was sexually violated in a school by a known perpetrator. The mother followed all protocols and procedures, but to date the perpetrator remains at large, based on the assumption that the victim has an intellectual disability and that this is not a winnable case.

A year later in August 2020, we received the news that a 16-year-old boy with Down Syndrome was allegedly shot by police in Eldorado Park. The case received wide media coverage, not because it was in the interest of justice but because a community had stood up demanding justice.

In that very same month, a 12-year-old girl with Down Syndrome passed away at a government hospital and her parents were only informed two months after her passing. This was only established after the family had insisted on seeing her.

While we only mention these few incidents, we are mindful that there are many untold stories of pain and suffering, and of families - not being able to secure justice for their family members. It should be noted that while the primary focus was mostly on women and girls with intellectual disabilities, we have through this project encountered an increase of sexual abuse cases against males with intellectual disabilities.

By developing this booklet, we hope to bring some measure of hope through the information shared so that persons with Down Syndrome and other intellectual disabilities and their families can access justice in South Africa.



"The new South Africa should be accessible and open to everyone. We must see that we remove the obstacles. Only then will the rights of disabled persons to equal opportunities become a reality."

- Nelson Rolihlahla Mandela, 1995

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List Of Abbreviations And Acronyms

AAC	▶	Augmentative And Alternative Communication
ADP	▶	Protocol To The African Charter On Human And Peoples Rights On The Rights Of Persons With Disabilities In Africa
CMH	▶	Cape Mental Health
CSO's	▶	Civil Society Organizations
CWID	▶	Child/Children With Intellectual Disability
DPO's	▶	Disabled Peoples Organizations
DSSA	▶	Down Syndrome South Africa
ID	▶	Intellectual Disability
FCS	▶	Family Violence, Child, And Sexual Offenses Unit
NDP	▶	National Development Plan
NGO's	▶	Non-Governmental Organizations
SAVE	▶	Sexual Abuse Victim Empowerment Programme
SAPS	▶	South African Police Service
STI's	▶	Sexually Transmitted Infections
PWID	▶	Person With Intellectual Disability
UNCRPD	▶	United Nations Convention On The Rights Of Persons With Disabilities



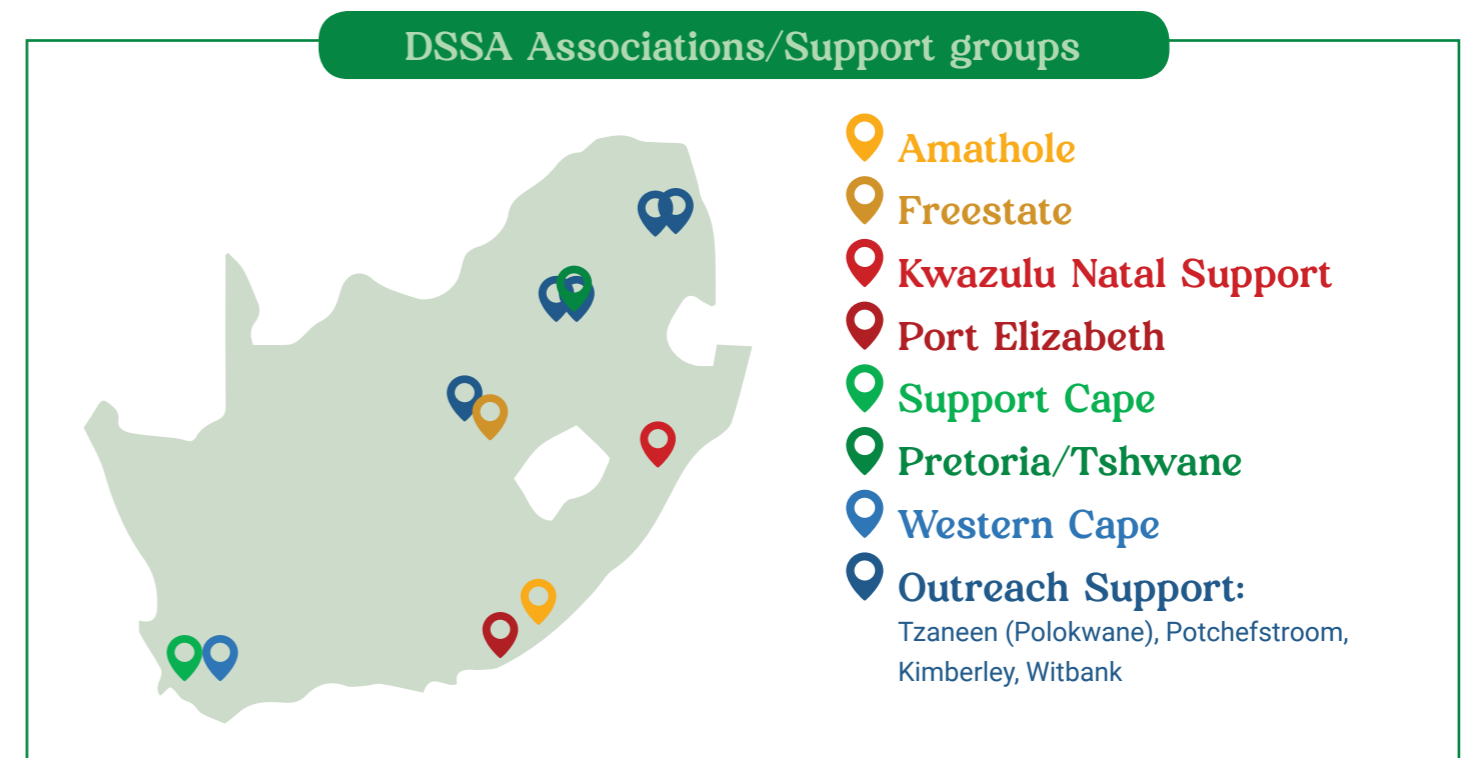
Glossary Of Terms

Augmentative and Alternative Communication (AAC)	AAC is used by individuals who have difficulty with speech and use different methods of communication such as gestures, manual signs, visual schedules or communication boards, computers or handheld devices with symbols that generate speech
Autism	Autism Spectrum Disorder is a developmental disorder that affects the nervous system
Caregiver	All people responsible for taking care of children and adults. This could be biological parents, extended family members, safety parents, foster parents, or caregivers in a home
Child Abuse	When someone involves a child in sexual activity, physically hurts their body or treats them badly emotionally
Child and Youth Care worker	Child and youth care workers work on the developmental needs of a child, youth, and family in a variety of settings through the implementation of preventative and therapeutic programmes
Criminal Capacity	The ability to appreciate the difference between right and wrong and the ability to act in accordance with this appreciation
Down Syndrome	Down Syndrome is a chromosomal condition caused by a partial or extra copy of chromosome 21
Fetal Alcohol spectrum disorder	Fetal Alcohol spectrum disorders are a group of conditions that occur in a person who was exposed to alcohol before birth
Forensic Social Worker	Forensic social workers work with individuals involved in the criminal or legal systems
Fragile X syndrome	Fragile X syndrome is a genetic condition that causes a range of developmental problems including learning disabilities
Neglect	Is when someone can protect and care for a person but does not do so
Perpetrator	Person who has committed a crime
Purpose of the Child's Justice Act	The Child's Justice Act allows the child's background or upbringing to be considered. It ensures that individual needs and circumstances of children in conflict with the law, are assessed before a decision is made on how to deal with the child's needs
Social worker	A social worker is a person who collaborates with vulnerable people, families or communities, helping them work through challenges they might face in everyday life
Trauma	Trauma is when something wrong happens that can hurt people physically or emotionally. It may be from a particular event or many horrific events over a long time
Victim	A person harmed, injured, or killed because of a crime, accident, or other event or action
Violence	Is when a person's body is physically hurt or harmed, or the person sees someone else physically hurt or harmed

1. Introduction

1.1 Down Syndrome South Africa (DSSA) as an organization

Down Syndrome South Africa (DSSA) is a registered non-profit organisation (NPO 009-415) and was formed in 1986 as the national umbrella body and parent advocacy organisation, promoting and protecting the constitutional rights of persons with Down Syndrome and other intellectual disabilities. DSSA currently has 12 regional associations and support groups throughout the country that provides services to persons with Down Syndrome and developmental delays, and their families.



Mission

Down Syndrome South Africa is committed to finding ways to improve the quality of life of all persons with Down Syndrome and other intellectual disabilities, promoting the idea that they have the right to live with independence, dignity, respect and security as valued children and adults and full citizens in society. It endeavours to empower families through the dissemination of information and

promotion of programmes on early intervention, education, health, employment, and civil rights. DSSA extends its care, support, and services to persons with intellectual disabilities, as well as those with multiple disabilities from all backgrounds in South Africa.

Programme focus areas

- ▶ Capacity building of our members in all nine provinces.
- ▶ Roll out of national projects on Early Intervention, Health, Education, Employment, Social Integration, and the Self-Advocacy Movement.
- ▶ Rights Based Advocacy on matters that affect persons with Down Syndrome and their families at national and international platforms.
- ▶ Awareness on Down Syndrome thereby reducing the stigma, myths and discrimination that surrounds the condition.

To read more on our organisation please visit:
www.downsyndrome.org.za

1.2 Purpose

The purpose of undertaking this project was to understand the context of justice for persons with ID, specifically those with Down syndrome in South Africa and the barriers they face when interacting with the justice system.

Persons with intellectual disabilities (ID) are the most marginalized and disenfranchised group in their communities. They face multiple challenges due to societal and systemic barriers, ranging from negative attitudes towards ID, isolation, high dependency on others to take care of their personal needs, poverty, lack of access to appropriate healthcare and poor educational outcomes.

Negative attitudes and social stigma towards intellectual disability, leaves persons with intellectual disabilities (PWID) without fair treatment, either as a victim, offender, or witness. They are viewed as unreliable witnesses due to their impaired capacity.

Research has shown that persons with disabilities, especially women and children, experienced increased vulnerability to violence, including sexual, physical, and psychological violence, neglect, and deprivation (McKenzie et al, 2015; van der Heijden et al, 2016).

Children with disabilities, especially girls are vulnerable as they live in relative isolation and are invisible to society. This situation has been compounded by the recent events around COVID-19 as most women and children were forced to stay at home behind closed doors resulting in an increase

in abuse cases. The justice system is not skilled to understand and handle cases of abuse in relation to PWID, this is evident in the lack of cases successfully prosecuted in a court of law.

“You do your best to assist but sometimes the criminal justice system lets you down, not because you did not do your best, but because the justice system is groomed this way, they do not adequately accommodate PWID.”

- Police Captain (FCS) unit

1.3 Study background

To understand the context of justice in South Africa for PWID, including those with Down Syndrome, we conducted a situation analysis through focus group discussions with families, health care professionals, social workers, care workers, educators, the police service, and civil society organizations working with ID in the field of justice. These discussions took place in four provinces of South Africa namely Gauteng, Free State, Mpumalanga, and Western Cape.

At the time of printing, we were not successful in getting participation from those within the judicial system.

The purpose of the study was to:

- ▶ Understand the barriers faced by persons with intellectual disabilities and their families when interacting with the justice system,
- ▶ Understand the gaps and how the different organs of government respond to situations of violence, abuse, and neglect when dealing with persons with ID.

1.4 Sample study

Based on the sample study during the focus group discussions, these were some of the questions posed and the respondents' responses:

1.4.1 What are the contributing factors that make PWID more prone to violence and abuse?

- ▶ Negative societal and institutional attitudes towards PWID,
- ▶ Lack of understanding of intellectual disability by parents and community,
- ▶ Neglect by parents,
- ▶ High dependency of others to take care of their personal needs,
- ▶ Lack of access to appropriate schools resulting in poor educational outcomes,
- ▶ Poverty – parent/s unable to hold down a job as they need to look after their child with disability,
- ▶ Lack of adequate housing – leaving children to wander the streets,
- ▶ Substance abuse by parent/caregiver.

1.4.2 Is lack of access to schools and education a contributing factor to making PWID more vulnerable to violence and abuse?

Because of shortage of educational programmes for children with intellectual disabilities (CWID), parents, in countries like South Africa, easily become unpaid caregivers because care burdens and lack of support hinder their pursuit of

employment (Geiger 2012; McKenzie & McConkey 2016). Being out of school also limits exposure of CWID to formal teaching on sexual health programmes. (Rohleder & Swartz 2009; WHO 2011).

“Lack of access to schools and poor educational outcomes does leave our children vulnerable and open to abuse.”

- Parents in Akkerville, Mpumalanga

“It is not always the centres or the schools fault, parents don't fully report what the child's condition is, they are reluctant because most times they are in denial. They don't disclose the correct information, they also are not consistent in sending their children to school. They don't understand their child's condition, nor do they attempt to teach them so they dump their children at the centre expecting that we must perform miracles. They also don't understand that it takes long for a child to understand certain concepts and when the child does not get it, they blame the teachers. Teachers are not doing their jobs, there is no co-operation from parents. They use the grant money to take care of the whole family instead of using it to assist the child with the disability, but I do understand their situation as sometimes they don't have a choice.”

- Care worker Stimulation Care Centre, Emalahleni

1.4.3 Why do parents not report cases of abuse?

- ▶ They do not understand reporting processes,
- ▶ When reporting, not taken seriously by authorities due to intellectual disability. The child is making up stories, cannot tell the difference between truth and lie. Cannot talk so how will child be able to testify,
- ▶ Parents want to protect their children and they don't want the community to know what happened because fear of stigma and judgement. Sometimes if the father is the perpetrator, the mothers protect their husbands or their marriage,
- ▶ Don't want to expose their children to secondary trauma.

1.4.4 What do you think Government must do to make your communities safer?

- ▶ They need to teach and distribute information to the community,
- ▶ Raise awareness on sexual abuse and violence throughout the year not only during 16 Days Of Activism,
- ▶ They must teach their employees about people with disabilities,
- ▶ They need to create awareness programmes about children with disabilities in mainstream schools. Schools need to be more inclusive so that other children learn about disability,
- ▶ Prioritize cases that are being reported to the justice system. Courts need to hire people who understand disabilities. Employ one person who understands disability at every institution,
- ▶ Provide counselling services to parents who have children with intellectual disabilities,
- ▶ Our police stations do not have counselling rooms,
- ▶ Religious leaders need to stop referring to children with intellectual disability as demons or being possessed by evil spirits.



The Constitution of the Republic of South Africa, 1996

The framework to conceptualize the protection of rights for persons with disabilities, is laid out in our Constitution and various other national and international legal instruments. The Constitution requires the State to respect, protect, promote, and fulfill the rights in the Bill of Rights.



“Everyone is equal before the law and has the right to equal protection and benefit of the law.”

The White Paper on the Rights of Persons with Disabilities (WPRPD), 2016

The vision of the WPRPD is the creation of a free and just society, inclusive of all persons with disabilities as equal citizens.

The WPRPD is intended to accelerate transformation and redress full inclusion, integration, and equality for PWD.

2. Constitutional, Policy And Legislative Framework

Access to Justice is inclusive of people's effective access to the systems, procedures, information, and the location used in the administration of justice.

The National Development Plan (NDP): 2030 Vision

Chapter 12 of the NDP envisages a country where people living in South Africa feel safe and have no fear of crime at home, at school, at work and they enjoy an active community life free from fear.

The Children's Act 38 of 2005

The Children's Act is a piece of law which consists of 22 chapters and gives effect to certain rights of children as contained in the Constitution.

Child's Justice Act of 2008

To give effect to certain rights as contained in the Constitution; to set out principles relating to the care and protection of children; to define parental responsibilities and rights; to make further provision regarding children's courts.

International and regional instruments

South Africa ratified the **United Nations** Convention on the **Rights of Persons with Disabilities** (UNCRPD) on 3rd November 2007, thereby indicating its willingness to be bound by and adhere to its norms and standards.

Article 12: Equal recognition before the law - "State parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law. State Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."

Article 13: Access to Justice - "Guarantees the right of persons with disabilities to access justice on an equal basis with others through the provision of procedural and age-appropriate accommodations."

The United Nations Convention on the Rights of the Child (CRC)

Article 12 (1) - "State parties shall assure to the child who is capable of forming his or her own views the right to express those freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child."

(1)"For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in any manner consistent with the procedural rules of national law."

Article 19 (1) - "State Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent (s), legal Guardian (s) or any other person who has the care of the child."

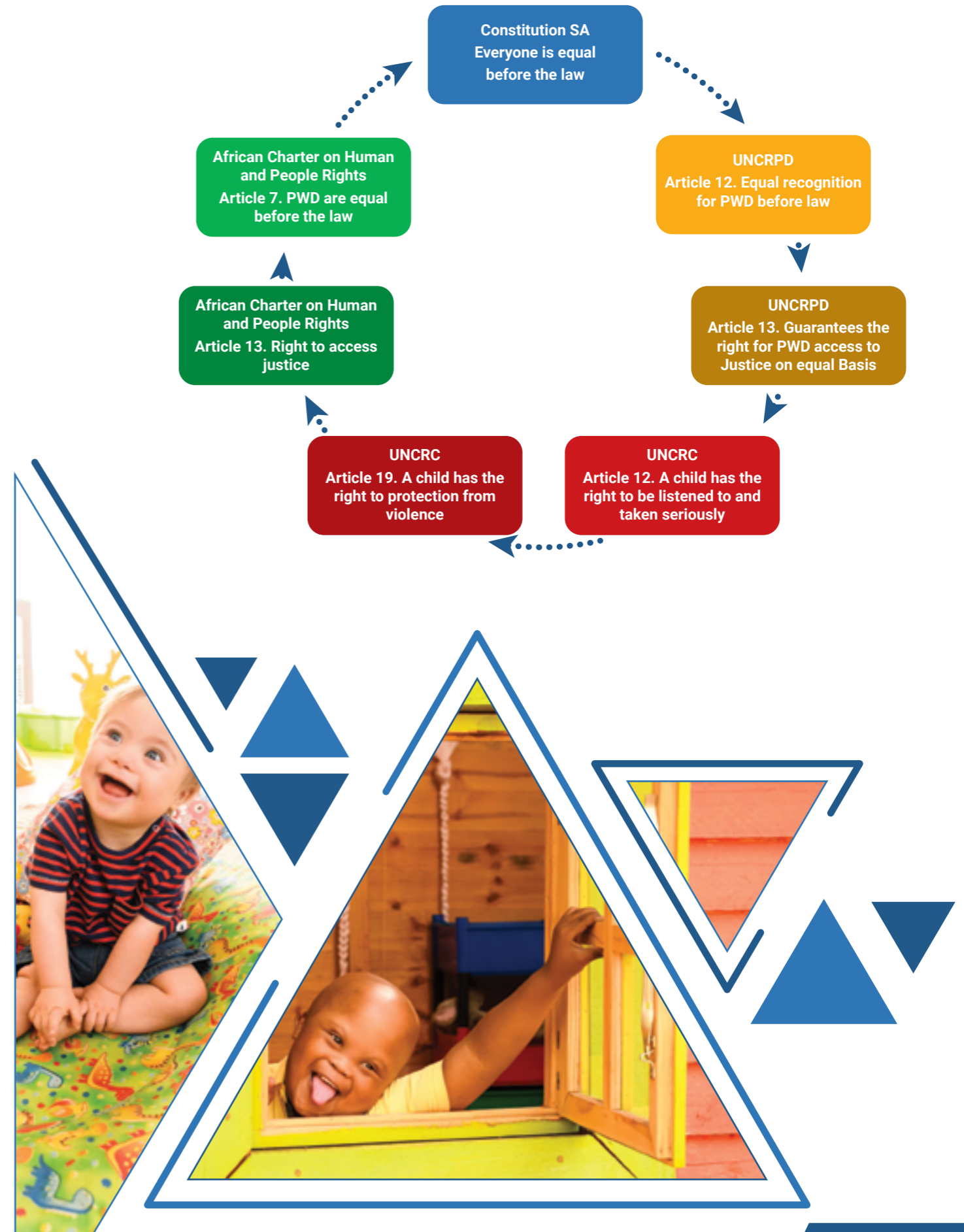
(2) "Such protective measures should, as appropriate, include effective procedures for the establishment of social programmes to provide necessary support for the child and for those who have the care of the child, as well as for other forms of prevention and for identification, reporting, referral, investigation, treatment and follow-up of instances of child maltreatment described heretofore, and, as appropriate, for judicial involvement."

Protocol to the African Charter on Human and Peoples Rights on the rights of persons with disabilities in Africa

Article 7 - "State Parties shall recognize that persons with disabilities are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law."

Article 13 - Right to Access Justice: "State Parties shall take measures to ensure that persons with disabilities have access to justice on an equal basis with others, including through the provision of procedural, age and gender-appropriate accommodations, in order to facilitate their effective roles as participants in all legal proceedings."

Poor implementation and monitoring of the various legal instruments expose many barriers for persons with ID when interacting with the justice system. The various articles contained in the UNCRPD, mandates the government of South Africa to fulfil its duty by ensuring that the rights of persons with disabilities are protected, including the right to access to justice on an equal basis as others.



3. What is an intellectual disability?

Intellectual disability is more common in low- and middle-income countries compared to those in higher income countries. This is due to a range of reasons, including increased risk factors such as poor nutrition, poverty, violence, increased exposure to environmental toxins and substance abuse during pregnancy. There are also fewer specialized intellectual disability services and programs to support PWID.

Many family members do not have sufficient understanding of their child's intellectual disability or what it means. This leads to lack of stimulation, negative attention, and exclusion towards the child, which can further delay development. Families and PWID can find themselves feeling isolated or confused. It is important to know that they are not alone and that there is hope and support.

Intellectual disability, cognitive disability, intellectually challenged, developmental delay and learning disability are all acceptable terms used in reference to persons with intellectual disabilities.

Intellectual disability is a term used when there are limits

to a person's ability to learn and function in daily life at an accepted level.

What are some of the signs of intellectual disability?

- ▶ Take longer to sit, crawl, or walk compared to other children,
- ▶ Learn to talk later, or have trouble speaking,
- ▶ Find it difficult to remember things,
- ▶ Difficulty with social interactions and understanding social rules,
- ▶ Have trouble seeing the results of their actions,
- ▶ Have trouble solving problems,
- ▶ Difficulty in communicating their wants and needs,
- ▶ Difficulty with self-care,
- ▶ Difficulty with learning in school

Intellectual disability can start any time before a child reaches the age of 18, even before birth. It can be caused by injury, disease, or brain abnormality. For many children, the cause of intellectual disability is not known.

Other causes of intellectual disability (such as asphyxia,) happen while a baby is born or soon after birth. Still other causes of intellectual disability do not happen until a child is older. These may include serious head injury, stroke, or certain infections such as meningitis.

It is important to note that levels of intellectual disability vary greatly and that every person with an intellectual disability should not be painted with the same brush, they have different abilities and can be supported to acquire some state of independence.

3.1 Types of intellectual disabilities

The standard method of measuring the level of functioning of a PWID is the intelligence test, using an intelligent quotient or IQ test.

A clinician can measure an individual's thinking and problem-solving abilities.

Most children with intellectual disabilities score in the range of 55-70.

The **5 most common types of intellectual disability** include:

- ▶ Down Syndrome
- ▶ Autism
- ▶ Fragile X Syndrome
- ▶ Fetal Alcohol Syndrome
- ▶ Prader Willi Syndrome

There are **4 categories of intellectual disability**, mild, moderate, severe, and profound.

3.2. The Difference between Mental Illness and Intellectual Disability

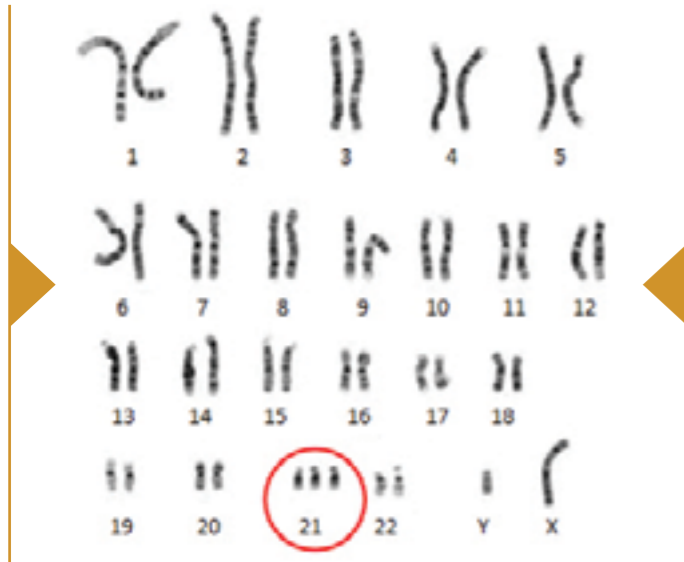
- ▶ It is important not to confuse an ID with mental health challenges or other illnesses.
- ▶ A mental illness is a temporary or long-term condition that can be treated with medication, psychotherapy, and other supports.
- ▶ Intellectual disability is a life-long condition of delayed intellectual development that can occur during conception, at birth, by injury or disease. It cannot be cured by medication.

Milestones	Age range for children with Downs syndrome	Typical age range
Gross Motor Skills		
Sits unassisted	6-30 months	5-9 months
Crawls	8-22 months	6-12 months
Stands	1-3.25 Years	8-17 months
Walks unassisted	1-4 years	9-18 months
Language		
First Word	1-4 years	1-3 years
Two-word phrases	2-7.5 years	15-32 months
Social/self help		
Smile	1.5-5 months	1-3 months
Finger feeds	10-24 months	7-14 months
Drinks from cup unassisted	13-39 months	9-17 months
Uses spoon	12-32 months	12-20 months
Bowel control	2-7 years	16-42 months
Dresses self unassisted	3.5-8.5 years	3.25-5 years

Categories of intellectual Disabilities

Mild ID IQ 50-69	<ul style="list-style-type: none"> May at first go undiagnosed May cope in a supportive structure Self-care skills usually good May struggle with abstract thinking May be able to read, write and do simple calculations May be able to be semi-independent May struggle with age-appropriate communication
Moderate ID IQ 35-49	<ul style="list-style-type: none"> Delayed pre-academic skills development May have limited reading, writing and counting skills Often unable to identify potentially dangerous or exploitative relationships Acquisition of skills can enable them to function with some level of independence or catch up with their peers.
Severe ID IQ 20-35	<ul style="list-style-type: none"> Often need assistance with bathing, eating and dressing Limited language Family members/caregivers usually provide ongoing support with daily activities Unable to read, write or count
Profound ID IQ below 20	<ul style="list-style-type: none"> Physical abilities always present Disability generally diagnosed at birth The person cannot walk/talk or take care of himself Depend on others for their care Limited conceptual thinking and language hinder development beyond simple tasks done with the help of family/caregiver

4. What Is Down Syndrome?



known as Trisomy 21.

This extra chromosome results in certain distinct facial characteristics and leads to both physical and intellectual delays. It occurs equally amongst all races, religions, and socio-economic backgrounds.

4.1 Prevalence of Down Syndrome

South Africa does not have specific data on the number of babies that are born with Down Syndrome. What we do know is that the prevalence rate is around 1 in every 500-750 live births. Down Syndrome can only be confirmed through a blood test.

4.2 Terminology and Myths

Myths associated with Down Syndrome

Down Syndrome is the most common occurring genetic condition caused by random error in cell division, which results in a partial or full extra copy of chromosome 21

Myth	Truth
<ul style="list-style-type: none"> ✗ Heaven's Angels or children of GOD ✗ Persons with Down syndrome are always happy and affectionate. ✗ People with Down syndrome all look the same. ✗ People with Down syndrome cannot achieve normal life goals. ✗ Only older mothers have babies with Down syndrome. ✗ People with Down syndrome do not live very long. 	<ul style="list-style-type: none"> ✓ This may lead to special treatment that can lead to special problems later in life. PWID grow up like everyone else. ✓ We are all individuals and people with Down syndrome are no different to anyone else in their character traits and varying moods. ✓ There are certain physical characteristics that can occur. People with Down syndrome can have all of them or none. A person with Down syndrome can take on the resemblance like his or her close family member. ✓ With the right support, they can. Most people with Down syndrome learn to walk and talk, and many are now attending mainstream schools, and living full, semi- independent adult lives. ✓ Although older mothers have a higher chance of having a baby with Down syndrome, more are born to younger mothers, reflecting the higher birth rate in this age group. ✓ Today, people with Down syndrome can look forward to a long life given the right medical attention.

False and harmful beliefs of disability can have a negative impact on persons with ID and their families. Most common cultural superstitious beliefs associated with PWID are:

- ▶ That it is a curse brought down by their ancestors,
- ▶ They possess evil spirits,
- ▶ Parents have sinned,
- ▶ They have super-natural powers that can cure AIDS and bring good luck.

Correct terminology to be used:

Correct Terminology	Incorrect Terminology
<ul style="list-style-type: none"> ✓ Person with intellectual/cognitive disability ✓ Person with Down Syndrome 	<ul style="list-style-type: none"> ✗ Person with mental health challenges ✗ Downsy ✗ Down Syndrome person ✗ Someone with Downs

Negative attitudes and cultural superstitious beliefs towards persons with ID may lead to behaviour that violates their human rights, this leads to stigma and segregation.

Words such as mental, retard, mongoloid, Downsie or Downs should not be used. Remember to always use person first language as the condition is secondary.

He/she is a person with an intellectual/cognitive disability. In reference to a person with Down Syndrome; he/she is a person with Down Syndrome.

“Words reflect as well as influence the way people think.”



5. Sexuality And Reproductive Health Rights

When it comes to addressing issues on sexuality and reproductive health rights for PWID, parental anxiety and societal prejudice makes this a difficult conversation to have.



“Parents don’t want to address the topic of sexuality. This applies to typical parents as well, especially in black culture. Parents fear addressing this topic. What’s disturbing is that while they don’t address it with their children, they expose their children to this because they watch certain TV programmes with sexual content, some parents are doing it right in front of their kids as most times they are living in 1 room house and they do this, thinking my child is disabled so they won’t understand what’s going on. Now the child comes to school and wants to do the same with the other kids.”

- Care Worker at a Care Centre in Mpumalanga

5.1. Myths that are associated to PWID around sexuality:

- ▶ That PWID are asexual and do not develop sexual interest as they will forever remain a child,
- ▶ That they are hyper and oversexed,
- ▶ PWID are unable to have sex as they have decreased needs for touch and affection,
- ▶ Do not recognise pleasure or understand the expression of love.

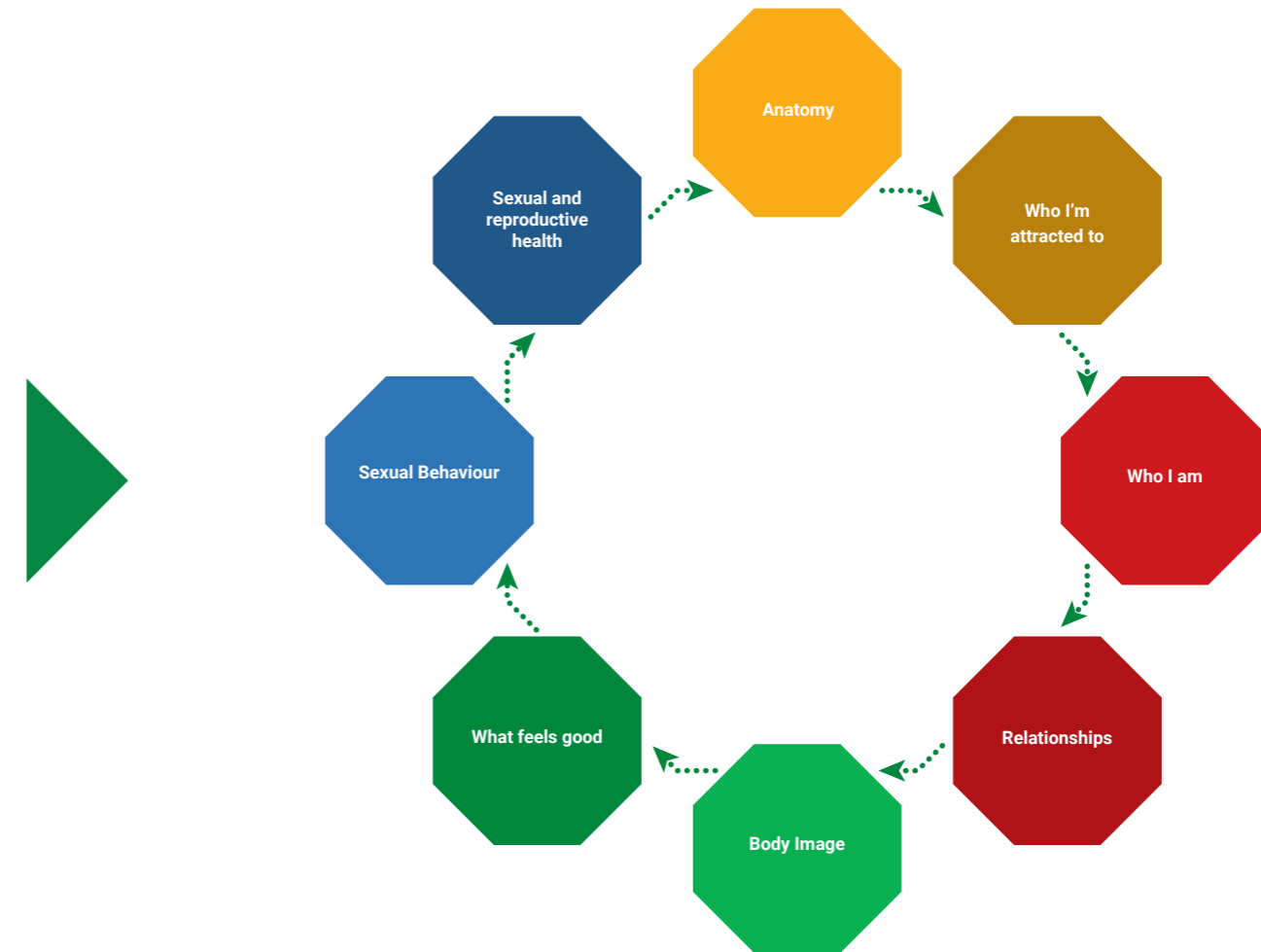
PWID like everyone have a right to emotionally satisfying and culturally appropriate sexual expression. They have the same feelings and desires as everyone else.

5.2 Why is it important for PWID to have access to information and skills to navigate sexuality?

- ▶ They are at higher risks to sexual violence and exploitation.
- ▶ They are at higher risk of HIV infection.
- ▶ They are at risks of unintended pregnancies and STI's.

PWID need information tailored to their level of cognitive functioning and learning style. The importance of sexual education and skills training leads to:

- ▶ Essential skills in self-care,
- ▶ Introduces more responsible sexual behaviour,
- ▶ Reduces inappropriate sexual expression,



- ▶ Facilitates healthy sexual behaviour and development,
- ▶ Reduces the risks of sexual violence,
- ▶ Leads to self-acceptance and self-confidence.

PWID should have access to routine reproductive health screening as they generally underuse gynaecological and reproductive services. In the past PWID were forced to undergo sterilisation without consent nor given any information on reproductive rights and contraception choices.

There is also the perception amongst some parents that sterilisation will prevent their child from being sexually abused.

The Sterilisation Act 44 of 1998; sterilisation can only be performed when:

- ▶ A person is capable of consenting; and
- ▶ 18 years or above,

- ▶ The consent form is signed,
- ▶ If the person is aware that consent may be withdrawn.

A panel of medical or social practitioners may contemplate sterilisation if the:

- ▶ Physical health of a person is threatened,
- ▶ There is no other safe and effective method of contraception,
- ▶ That the person’s intellectual disability is so severe to the extent that such a person is incapable of making his or her own decision.

6. What Is Access To Justice?



what recourse mechanisms are available should they experience discrimination or exclusion, and know how to access these recourse mechanisms.

The protection and promotion of human rights for persons with disabilities is an underlying principle in all the articles on the UNCRPD.

“Access to Justice”, is inclusive of people’s effective access to the systems, procedures, information, and locations used in the administration of justice. The ability to access justice is of critical importance in the enjoyment of all human rights.

To be fully included in society, PWID need access to justice. If they face barriers to their participation in the justice system, they will be unable to assume full responsibility as members of society or experience their rights and enjoy equal opportunity to perform their duties either as a witness, complainant or accused.

To understand the concept of ACCESS TO JUSTICE, PWID and their families must understand what their rights and entitlements are, know

6.1 What is a Human Rights Violation?

A human rights violation is defined as an abuse or violation of any of the rights found in the Constitution. If human rights are violated, the courts or other bodies with the power to make determinations about such violations may be approached for assistance.

6.2 Sexual abuse at schools

It is important to note that abuse towards a PWID does not only happen in the home but also in schools. This abuse remains largely invisible despite estimates that this is perpetrated more frequently than against those without disabilities. Due to communication barriers PWID are often targeted for bullying and abuse as they are socially more isolated than their peers.

For PWID abuse at school can take on many forms i.e., bullying, teasing, physical abuse such as slapping, hitting, pushing, and sexual and emotional abuse.

In most cases abuse can be perpetrated by peers, educators or support staff members assigned to support the PWID.

Addressing school violence and bullying against all learners, including learners with disabilities is imperative to avoid dire consequences such as missing classes, avoiding school activities, and dropping out of school, which negatively impacts academic progress and future employment prospects.

Girls with disabilities are extremely vulnerable and require added protection from abuse. Education policies need to be reviewed to ensure alignment to the UNCRPD for all children with disabilities against school violence and bullying. Despite South Africa scoring the highest points in terms of its policy on the Protocol on the Management and Reporting of Sexual Abuse and Harassment in Schools, gaps remain in ensuring that learners with disabilities are addressed in this policy.

Disability awareness is key within schools, but efforts must extend beyond schools, to parents and the wider community. Many parents and community members have no expectations of success for children with a disability, and do not find the need to invest in them.

IMPORTANT INFORMATION: Schools are mandated to assist victims of sexual abuse and harassment by following standard reporting procedures and through the provision of appropriate support to learners.

6.3 Barriers To Accessing Justice

PWID have varying degrees of intellectual capacity, they also come from different socio-economic and socio-cultural backgrounds that can hamper their access to justice. Barriers hindering persons with disabilities and their families from either using the justice system when they feel wronged or mistreated, or limiting their contributions to the administration of justice, include:

- ▶ Poverty,
- ▶ Geographic location of courts,
- ▶ Physical inaccessibility of courts,
- ▶ Lack of knowledge on legal rights and recourse mechanisms,
- ▶ Lack of access to legal representation,
- ▶ Lack understanding of reporting and procedural processes,
- ▶ High costs associated with litigation processes,
- ▶ Delays in the resolution of disputes.





“My child was 15 when she was raped in 2004 by a family friend. She told me who did it, we went to the police to lay a charge, the police arrested him, but he was released on bail. He could hire a lawyer to dismiss all the charges - they did not listen to my child’s side and because we could not afford lawyers, I left it.”

- Parent in Akkerville, Mpumalanga

Potential Legal Implications for persons with Mild Intellectual Disability

- ▶ Usually, persons with mild intellectual disability can be sworn in as a witness and testify reliably,
- ▶ They should be seen as vulnerable. Court preparation is necessary, and the person may require a simplified oath, an intermediary and care under cross examination,
- ▶ More time might be needed.

Potential Legal Implications for persons with Moderate Intellectual Disability

- ▶ Person with moderate ID may be able to give reliable testimony, but will need more support than persons with mild ID,

WHAT IS ACCESS TO JUSTICE?

- ▶ They are often able to differentiate between truth and lies, but this needs careful assessment using familiar concepts and concrete examples,
- ▶ A simplified oath is required,
- ▶ Usually their account is simple, and the person is unable to provide times and dates,
- ▶ These complainants may be misled on cross-examination, but the risk of this can be reduced with the help of a support person,
- ▶ More time might be needed.

Potential Legal Implications for persons with Severe Intellectual Disability

- ▶ They may even require more support to testify,
- ▶ It may be hard to show that the person understands the difference between truth and lies – not because they readily tell lies, but because they often cannot understand the question. This can exclude them from testifying even when they can provide an account of the alleged offense,
- ▶ Their account may lack consistency on the sequence of events,
- ▶ The complainant in this category can easily be misled by leading or complex questions, but this risk can be reduced with the help of a support person,
- ▶ More time might be needed,
- ▶ If found competent as a witness, an intermediary will always be recommended.

Potential Legal Implications for persons with Profound Intellectual Disabilities

- ▶ Someone falling into this category will not be able to act as a witness,
- ▶ Court cases will depend on witnesses and/or forensic evidence.

UNDERSTANDING LEGAL CAPACITY

7. Understanding Legal Capacity

Many persons with intellectual disabilities are deemed not to be legally competent to assert their rights in accessing justice.

Legal capacity is the ability to bear Rights and Responsibilities. Making decisions is an important part of our everyday living experiences. We make decisions about where to live and whom to live with, to enter marriage, what is best in terms of our healthcare needs, our education, about employment and about our financial needs.



“Making decisions allows us our individual identity and allows us the freedom to take charge of our lives.”

Understanding Legal Capacity

Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) recognises that persons with disabilities: “enjoy legal capacity on an equal basis with others in all aspects of life” and that disability alone does not justify the deprivation of legal capacity.

Where competence relates to the ability to do something successfully or efficiently, capacity speaks to legal independence and participation during legal proceedings (UN 2006). The ability to participate fully in daily life experiences builds competency.

In South Africa the legal procedures as set out in **The Mental Health Care Act, 17 of 2002 and The Criminal procedure Act, 51 of 1977**, has left many PWID without a say in matters that directly affect them.

PWID are usually denied the opportunity to make decisions in this way because of preconceived ideas, myths, and prejudices about their “capacity”, as well as their communication barriers. Important decisions are made through a system called substituted decision-making versus supported decision making.

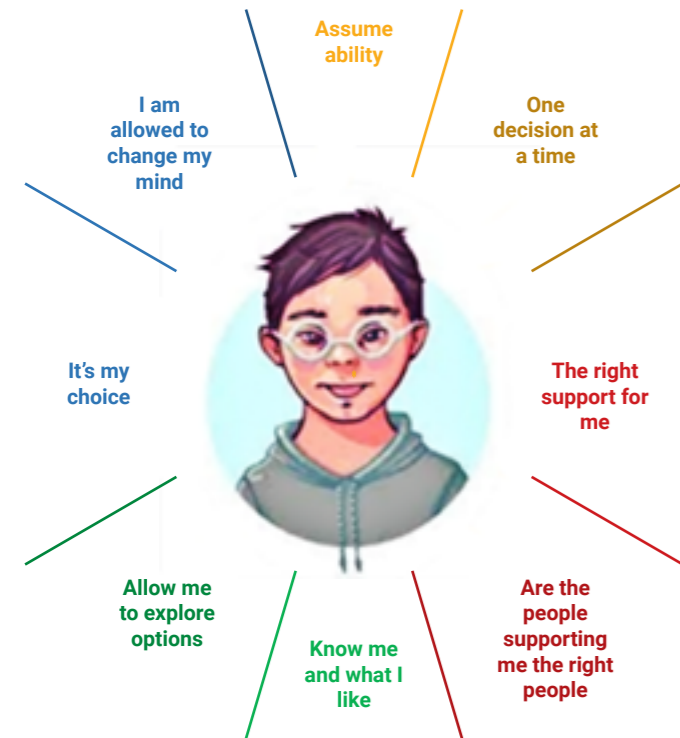
Laws, policies, and practice that deny persons with intellectual disabilities their right to legal capacity claim to do so in their best interest and substituted decision-making by individuals and institutions who are deemed to be better placed to make the decisions and take actions on their behalf.

7.1 Supported Decision-Making

Why is the right to decide so important for people with intellectual disabilities?

- ▶ It helps them develop a sense of control over their own lives,
- ▶ It teaches them that they are responsible for themselves and that they have a responsibility towards others,
- ▶ It helps them to become more assertive and therefore, less dependent, and less vulnerable to exploitation; and
- ▶ It helps them to develop positive and healthy relationships with others.

When people are supported to make decisions for themselves, they are seen as more capable by others. When they are not allowed to make their own decisions or when someone makes those decisions for them, they are seen as less capable and as having less value in a community.



Supported decision-making can take on many forms, here are some accommodations and supports in decision-making:

- ▶ Extra time to make decisions,
- ▶ Information in plain language or Easy Read,
- ▶ Informal assistance,
- ▶ Support to build self-advocacy capacity.

Supported Decision Making

- ▶ Peer support,
- ▶ Advocacy,
- ▶ Personal support networks, formal representation agreements, or key supporters for assistance with some or all decision making,
- ▶ Communication supports like assistive technology, interpretation, or translation.

Decision making in complex situations

- ▶ This is support when decisions are complex or when a person requires significant support or does not use traditional communication. It is important to remember that even a person with significant disabilities, is a person first with a history, interests and aims in life.

7.2 Easy To understand Language

The United Nations General Assembly has recently passed a resolution to adopt Easy to Understand Communication for accessibility for persons with Disabilities. It encourages governments to make more efforts to deal with barriers that make information, communications, and other services accessible to PWID.

When people communicate through emails, websites or through social media, PWID often miss these types of communication simply because it is difficult to read and understand. When testifying in a court, PWID should be able to have access to easy-to-understand communication to enable them to testify effectively.



”At our Care Centre we had a case where a child was raped, the abuser was identified with the support of the community and arrested. When case was brought before the court, she was brought face to face with her abuser and was forced to testify in front of him. She was already afraid, also the prosecutor insisted she give intimate details of the assault using words that she was uncomfortable with and could not understand. She simply could not give a detailed account, not because the rape did not take place but rather that she was not presented with other means of communication. She could not say he removed my panties and used his penis to enter my vagina and raped me, because of this the case was thrown out.”

- Care worker at Care Centre

There are different formats of easy-to-understand communication, no one format will work for everyone.

7.3 Types of Communication:

- ▶ Easy to read in print form,
- ▶ Signing or gestures,
- ▶ Visual or tactile information (pictures or concrete objects),
- ▶ Others require audio and videos,
- ▶ Augmentative and Alternative communication, (communication boards that generate speech).



8. How Can I Access Justice?

8.1 The Child Protection System

The Child Protection system is guided by the Children's Act 38 of 2005. The Child Protection system must be co-ordinated and managed by various government departments to ensure that the child's rights are protected.

Parents are the primary caregivers and protectors when it comes to their children's care and safety. Sometimes, however, this is not possible for everyone, and this role can be taken over by alternative caregivers, such as siblings, extended family members (kinship caregivers) or community members.

PWID who have been sexually abused can be scared and confused and their family members don't often understand the criminal justice system and do not know where to go for support.

When there is a case of suspected abuse or neglect, the magistrate at the Children's Court must be involved to decide the best place of safety for the child and can place a child in an alternative care facility.

Alternative places of care can include:

- ▶ **Place of safety parents** – Looks after the child for a short time, usually not longer than 3 months, while the investigation is still going on.
- ▶ **Foster care parents** – Looks after the child for up to two years after the investigation is complete. These cases are monitored and re-evaluated by social workers to see if the child will continue to stay on with their foster parents, go to a children's home, or return to their home.
- ▶ **Kinship caregivers** – these are people from the child's extended family (grandparents, aunts, uncles, cousins) who take the child into their care for safety.
- ▶ **Child and youth care centres, or children's homes** – care for the child when there are no other options of alternative care. They are taken care of by Child and Youth Care workers.

Child and Family Social Workers

Child and Family social workers are called in to investigate suspected cases of abuse and neglect. They provide services to help families stay together by working with the family. They can develop plans to help the family's support needs, such as counselling, parenting skills, or medication, they also work with the children's court to put a plan of action together for the child's safety.

8.2 The Reporting Process

It is important to know the following when reporting a case of suspected abuse:

- ▶ Reporting to the police,
- ▶ The medical examination,
- ▶ Where to get help and support.

South African Police Service (SAPS)

The South African Police Service (SAPS) is responsible for preventing crime, maintaining public order, and protecting all people in the country. Whenever, there is a suspected case of abuse, the matter must be reported to the police.

The following process must be followed:

- ▶ A sexual offense complaint can be received by telephone, or the victim can present themselves at their nearest police station,
- ▶ If a complainant/victim presents themselves at a police station outside their jurisdiction of either the victim's home, or where the alleged rape/sexual offense took place, then the case must be dealt with by the station where the offense is being reported and be treated as if the offense had happened in their area,
- ▶ An accountable adult person should accompany a victim with an intellectual disability and be present when the statement is taken,
- ▶ The matter must be given immediate attention and no

victim should be turned away. Any medical emergency should be attended to immediately,

- ▶ They should treat the matter as sensitive and take you to a safe space, either a quiet space away from the main desk or a victim support room, where you can be counselled, and your statement taken,
- ▶ The first officer receiving the compliant must open a docket and provide you with a case number. Where the case was reported outside their jurisdiction, the docket must be sent to the victim's home station once the necessary actions have been taken,
- ▶ The statement may be taken as soon as you report it or after you have been medically examined by an accredited health care practitioner,
- ▶ You will have to tell the officer taking down the statement exactly what happen,
- ▶ The police officer taking down your statement is usually not the investigating officer,
- ▶ The first officer must reassure victim and accompanying adult and explain police procedure, The first officer must also contact the investigating officer as soon as possible,
- ▶ The investigating officer must take down your statement by completing the 308 form and refer you for medical screening. Medical evidence is crucial and must take priority over taking of a statement. The medical examination must be carried out by an accredited health care practitioner, and all information entered onto a J88 form,
- ▶ Should the victim with an intellectual disability not be able to communicate the abuse, the adult accompanying the person should explain what happened, provided that the adult is not a person who witnessed the crime. The investigating officer should contact a specialised worker who is able to assist with communication barriers,
- ▶ You have a right to request a copy of your statement,
- ▶ It is important to inform the investigating officer immediately of any change of address or telephone number, so he can get in touch, when necessary,
- ▶ The investigating officer will gather all the information

on the case. Once the case goes to court, a lawyer appointed by the state will represent you,

- ▶ Should you not have access to a lawyer, you can approach Legal Aid South Africa,
- ▶ Where the victim is under 18 years old the Child Protection Unit/Specialised (FCS) worker must be contacted, such as forensic social worker,
- ▶ The safety of the child must be secured by arresting the perpetrator or by placing a child in a place of safety.

Medical Screening (J88 form)

A medical examination will be undertaken to confirm that a sexual abuse has taken place and to collect evidence to present in a court.

- ▶ The medical procedure must be explained to put the victim with an intellectual disability at ease,
- ▶ The medical screening must be conducted by an accredited health care practitioner,
- ▶ The medical report, known as a J88 form must be completed by the medical examiner,
- ▶ This information will serve as evidence in the court,
- ▶ It is important that a victim should not change his/her clothing nor wash himself/herself as evidence could be lost,
- ▶ Any immediate concerns around possible pregnancy or sexually transmitted diseases, the medical examiner can provide you with medication to prevent this if it is safe to do so,
- ▶ In the event of a pregnancy an abortion could be granted if it is safe to do so.

HOW CAN I ACCESS JUSTICE?

A prosecutor is a lawyer working for the state and represents the interest of a person who has opened a criminal case against a perpetrator.

Magistrate/Presiding Officer/Judge

The magistrate in a children's court is not the same as the magistrate in a criminal court.

The magistrate will listen to all the facts about the case and make the final decision of whether the person is guilty or not.

Intermediaries

Some courts have specially trained people, called intermediaries who can help a child or a person with an intellectual disability in a court of law. The appointment of an intermediary is based on the assessment done by a social worker or a psychologist. If it is believed that due to the emotional and cognitive functioning the PWID will require support in delivering testimony, the prosecutor can request the appointment of an intermediary. Parents can approach the prosecutor to have an intermediary appointed, the final decision however, lies with the judge based on the assessment.

In some cases, the intermediary sits in a separate room away from the courtroom with your child, to help them feel safe and to avoid undue stress and anxiety.

The intermediary has basically two main functions:

- ▶ To protect the CWID against hostile cross examination, and
- ▶ To assist the CWID to understand the questions asked.

The Types of Courts dealing with Sexual Offenses:

Children's Court

The Children's court is a special court which deals with issues affecting children under the age of 18 years. The children's court takes care of children who need care and protection and makes decisions about children who are abandoned, neglected, or abused.

HOW CAN I ACCESS JUSTICE?

If a child needs to be removed from the parents care due to alleged sexual abuse, then the matter will be referred to the children's court. The child might need to testify but the courts will be sensitive during the child's testimony and will assist according to their procedures which entails provision of a psychologist, or social worker with forensic assessments/evaluations and recommendations to whether a child is intellectually/emotionally able to testify.

The presiding officer or judge at the Children's court must listen to all the facts about the case and will have to decide based on the facts on what is best for the child. The social worker will present his/her report to the judge, but children, parents and caregivers will also have a chance to tell their side of the story.

For those in conflict with the law:

The Child's Justice Act, Act 75 of 2008, is aimed at protecting the rights of children who are in conflict with the law. This means that children between the ages of 12 and 17, who are suspected to have committed a crime, will receive additional protection through procedures aimed at preventing them from obtaining criminal records, in appropriate cases.

Children under the age of 12 are deemed not to have criminal capacity and cannot be charged or arrested for an offense. In such a case the child will be referred to a probation officer.

Sexual Offenses court

The Sexual Offenses Courts are special court rooms that deal with sexual offenses, such as rape for both children and adults.

In the case of a child the Children's Act will come into play and certain accommodations such as an intermediary and in camera testimony will be allowed.

In the case of an adult with an intellectual disability, the judge can decide based on the assessment whether to treat the case in the same manner as that dictated by the Children's Act.

Where families are not able to afford legal representation, the court will appoint one.



People to reach out to for Support

It is always important to remember that you are not alone and that there are people or organisations that you can reach out to for support.

- ▶ Child and family social worker at your nearest clinic or provincial hospital,
- ▶ Your family doctor,
- ▶ Spiritual leader in your community,
- ▶ Guidance teacher or psychologist at school,
- ▶ Rape counsellor,
- ▶ Child Line (08000-55-55-5),
- ▶ Non-Profit organisations dealing with intellectual disabilities.

8.3. The Criminal Justice Process

All legal proceedings to deal with a perpetrator who committed a crime against a person is dealt with in a criminal court, which is different from the children's court. The job of the court is to look at evidence to see if the person accused of committing the crime is guilty or not.

The people you might meet when dealing with the criminal justice system:

Forensic Social workers

Forensic social workers assist the criminal court to speak to children about the trauma they suffered and to hear their story in their own words. They also help the court to establish if the child is ready to testify in court.

Prosecutor

Conclusion

South Africa has norms and standards to guide procedural processes when it comes to accessing justice, however many gaps exist in its implementation. It is not consistent throughout the country as many do not have the facilities to implement these norms and standards. Huge gaps remain in identifying best practice in terms of intellectual disabilities in court procedures as well as the lack of introducing easy to understand communication so that persons with intellectual disabilities can have their day in court.

The SAVE programme, developed by Cape Mental Health has the potential to bring about transformational change throughout the country but due to lack of funding this service is sadly only available in the Western Cape.

Important Contacts for Support

Cape Mental Health

- 🌐 capementalhealth.co.za
- ✉ info@cmh.org.za
- ☎ 021 447 9040

Childline

- 🌐 childlinesa.org.za
- ✉ admin@childlinesa.org.za
- ☎ 031 201 2059 (National Office)

Commission on Gender Equality

- 🌐 cge.org.za
- ☎ 011 403 7182

Department of Education

- ☎ 012 312 5911

Department of Justice

- ☎ 012 315 1111

Department of Social Services (Gender Based Violence)

- 🌐 gbv.org.za/about-us
- ☎ 012 312 7500

FAMSA

- ☎ 0800 150 150 (National Helpline)

Jelly Beanz

- 🌐 jellybeanz.org.za
- ✉ info@jellybeanz.org.za
- ☎ 021 556 2456

Legal Aid South Africa

- State funded institution that provides free legal assistance for those who cannot afford legal aid**
- 🌐 legal-aid.co.za
- ☎ 0800 110 110

National Child Rights Committee

- ☎ 011 807 7474/5/6

Resources aimed at the Prevention of Child abuse and Neglect (RAPCAN)

- ☎ 021 448 9034/5/6/7

Public Protector South Africa

- To lodge a complaint**
- 🌐 pprotect.org
- ☎ 012 366 7000

South Africa National Council for Child Welfare

- 🌐 childwelfare.org.za
- ✉ national@childwelfare.org.za
- ☎ 087 866 1516

South African Federation for Mental Health

- 🌐 safmh.org
- ☎ 011 781 1852

South African Human Rights Commission

- 🌐 sahrc.org.za
- ☎ 011 484 8300

SAPS

- ☎ 10111

Teddy Bear Clinic

- 🌐 teddybearfoundation.org
- ✉ shahedao@ttbc.org.za
- ☎ 011 484 4554

Thutuzela Care Centre

- 🌐 https://gov.za/TCC

Additional Resources for Support

National Department of Education: Protocol for The Management And Reporting Of Sexual Abuse And Harassment In Schools

Department of Justice and Constitutional Development

www.justice.co.za/Resources/Publications

<https://www.justice.gov.za/vg/gbv/201903-GBV-SummitDeclarationBooklet.pdf>

https://www.justice.gov.za/docs/InfoSheets/2008%2002%20SXOactInsert_web.pdf

https://www.justice.gov.za/brochure/2019_GBVF_NewspaperSpread_Nov.pdf

<https://www.justice.gov.za/vg/cj/2019-ChildJustice-bookletA6.pdf>

<https://www.justice.gov.za/brochure/2019-PWD-HandyHintsForCourtOfficials.pdf>

<https://www.justice.gov.za/faq/faq-sorma-intermediaries.html>

https://www.justice.gov.za/vg/cj/2015-ChildJusticeAct-Info_Chart_online-SAPS.pdf

<https://www.justice.gov.za/vg/sxo/2013-sxo-intermediary-services.pdf>

https://www.justice.gov.za/brochure/2011_childrens-rights-are-cool.pdf

https://www.justice.gov.za/brochure/2011_childrens-act-pamphlet.pdf

https://www.justice.gov.za/brochure/1998_law-talk-doc.pdf

https://www.justice.gov.za/brochure/1998_victims%20of%20sexual%20offences.pdf

<https://section27.org.za/wp-content/uploads/2016/04/Someone-Hurt-Me-64pg-LRES>

<https://www.justice.gov.za/forms/other/J088.pdf>





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