

March 2023

With us NOT For us



Message from the National Executive Director

WORLD DOWN SYNDROME DAY – 21ST MARCH 2023



The right to legal capacity is the ability to bear Rights and Responsibilities, making decisions is an important part of every day living. Making decisions on where to live or with whom to live, getting married and having a family, opening up of a bank account and managing one's own finances or choosing one's healthcare needs are just some of the decisions that are important to us to maintain our own identity.

Understanding legal capacity can be a complex issue, it is even made more difficult when looking at it from an organisation's perspective representing persons with Down syndrome or from a parent's perspective.

Our Constitution is based on the premise that everyone should enjoy the same liberty and freedoms, irrespective of whether a person has a disability or not.

As an advocacy organisation, one is compelled to look at it from a Human Rights angle, as too many people have fought hard in the promotion and protection of the rights of persons with disabilities. The Convention on the Rights of Persons with Disabilities (CRPD) is evidence of this.

As a parent however, one takes on the role of carer and protector. Finding the right balance between allowing your child their individual autonomy to make their own choices or to make those choices for them can become a sensitive issue. As parents we are guided by our intuition to protect our children from harm and sometimes making those choices for them is because we believe we are acting in their best interest.

Whatever our intentions, we must always be open to the fact that our children's opinion and voices matter. As organisations and as parents we need to ensure that we bring in the correct support and communication tools to allow them to exercise their right to choose.

Read our Media release for WSDS [here](#)

Together we can all make a difference.

Throughout March we will be sharing key messages on legal capacity, good practices on supported decision-making and easy-to-read communication. Join this discussion and follow our campaign "With Us not for US" by liking, sharing and commenting on our posts.



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A siblings story

I'd like to speak up for those who take over the responsibility of care for adults with Down Syndrome.

It might be a sibling or a relative. There is a system and support available to parents with babies born with Down Syndrome. It's not a perfect system, and the support is probably not sufficient, but at least some help and framework exists. However, there is nothing in place for the siblings who, for whatever reason, need to take over the care of their brother or sister in their later years. And what makes this especially painful, is how costly, complicated and painfully long the legal system in South Africa makes this process.

What it means to be a sibling and to become a guardian in South Africa

I've been a big sister to Karel, for as long as I can remember. Before I knew how to write my name. Before I could tie my laces. Before I knew what colour my hair would be. A parent steps into this role as an adult with a range of interests and, to an extent, a sense of self. But we are born into it.

We can't imagine a life without an awareness of Down Syndrome. We immediately recognise it around us. We nod to the parents as they stroll past with children we've never met but somehow feel a connection towards. Just because we don't resemble the hallmarks of Trisomy 21 in our faces, that doesn't mean we don't live it. We often go by under the radar, somewhat invisible. If you have a sibling with Down's Syndrome, you'll understand how this sibling role shapes your childhood and perhaps one day, your own children's lives too.

As if this isn't enough, in South Africa, you're also faced with roughly R60 000 in legal fees and at least one year of bureaucracy, just to get the sheet of paper that gives you the legal capacity to *become* a guardian. What if, like me, your parents didn't have a plan and didn't make provision for either of you? What if your parents left it to you to work out alone? You'll have a lot to grapple with, not least the law itself. Because in South Africa we don't even *use* the word "guardian". Instead we require the sibling to be appointed as a "curatrix ad bonis" and a "curatrix ad personam" via an archaic legal system involving lawyers, advocates and the High Court of South Africa itself. During what is already a harrowing time, you'll have no ability to bypass this legal hurdle, no matter what the circumstances. Like I did, you might email the social services and they probably wouldn't have heard of these Latin terms, never mind have advice to offer. You might email the Down Syndrome Association of South Africa in search of a loophole and will soon understand that no such thing exists. You'll have to dig into savings and or take out a loan, and you'll feel guilty for the strain this is placing on your own family. The law made our transition into guardianship unspeakably difficult and I'll explain why.

This is how it unfolded for us

It happened in 2021. I was 39, and had emigrated to Slovenia four years prior with my husband and our two children, then aged 10 and 14. In fact, they had only just celebrated their birthdays when we got the news that my mother had passed away. Her funeral was held one day before New Year's Eve. We entered 2022 knowing a lot of uncertainty lay ahead for us.

As the funeral arrangements took their course, I shifted the focus onto Karel and his care. I knew that I couldn't speak to our dad about Karel, because he had abandoned me after he divorced my mother when I was five. While Karel was placed in my dad's care, he had placed Karel in institutionalised care until my mother managed to have Karel live with her. In fact, the only text message I have ever received from my dad was offering me his condolences after we lost our mother. Needless to say, his text message added to the depth of loss I felt as I read it. I still don't know how to respond to it.

At least I had the support of my stepdad of 23 years, or so I thought. My mother had worked alongside him in his evangelical ministry, and as he was the financial director of a large group of churches too, I assumed he would have made a plan for my brother. I soon learned that there was no plan, no savings, no life insurance policy, nothing.

And as he put it, Karel could live with him *as long as his circumstances allowed it*. When I prodded what that

meant, he revealed that a change of circumstances meant, "Until God gives me a new wife".

Now this was a lot to take in within a week of the funeral.

The first task at hand was to work out how Karel could come live with us. We visited the immigration office that week and were told we needed to have a document from a South African court appointing us as guardians in order for my brother to have the right to emigrate. This seemed simple and sensible enough. I contacted a few lawyers (over 15), yes my phone bill suffered that month. And the reality dawned on me that it would take one year for the paperwork, and cost between R45,000 and R60,000!

But thankfully my stepdad had said Karel could live with him until his circumstances changed. So at least I didn't have to worry about *where* Karel could live while we sorted the legal documents out. But on the 24th of March, my step dad sent a message on WhatsApp stating that Karel could no longer live with him and that we would need to bring him to Slovenia in May, or he would have no choice but to send Karel to my Dad. My Dad in turn responded with a letter stating that he would have no choice but to hand Karel over to the state. I asked my stepdad to reconsider his position, but he simply stated that his position was non-negotiable.

The situation was unbelievably tricky because we needed a Schengen visa for my brother in order to bring him to Slovenia. And once in Slovenia, we needed that High Court appointment document to give us the legal capacity we need to apply for his residency permit. Along with a Police Clearance Certificate from the SAPS - and all documents must be apostilled. I recognise that our situation was complex due to the family dynamics or lack thereof, and because we live abroad. However, if any sibling were to take over care in South Africa, they would need the same legal document from the High Court to open and manage a bank account on behalf of someone else, and to make medical decisions for example. The legal hurdle still stands regardless.

Thankfully, we had found good lawyers due to the amount of legal professionals we contacted early on. Our lawyers decided that the actions of my stepdad and dad had justified an appeal for an emergency hearing at the High Court in order for my brother not to be made a ward of the state. And it worked. We had an emergency hearing set in April where we could make the case for an emergency application.

Our case file was well over 100 pages long with all the evidence we could provide about Karel's current and past situation. I can't disclose everything but suffice to say, Karel was in immediate need of assistance, and needed different living arrangements urgently because his current situation had placed him at considerable risk of harm.

The hearing date came, and in an unprecedented outcome, the court not only considered that Karel's case warrants an emergency hearing, but that they can do away with the protocol requiring at least 3 further hearings involving an additional advocate of the High Court. Instead they decided on that very day to appoint me as Karel's curatrix ad bonis and curatrix ad personam. This was a small token that there is good in this world. Our lawyer called us in tears as she conveyed this extraordinary news. She had never heard of this taking place before. The judges who oversee these complex cases are themselves doing their best to work within a rigid and dated legal system. And in our case they did away with the complex steps in the system. But if our case had not been so unfortunate and desperate, the usual steps would have taken precedent. A system which itself requires an urgent application to be modernised.

What happened in the end?

We still had to pay the legal fees, and the bill came in at slightly over R60,000 due to the paperwork required to present Karel's situation. Ironically our dad paid R20,000 towards this. This is the only contribution he made towards anything for most of my life having successfully evaded child maintenance contributions so effectively. It clearly was important to him that I take over Karel's care. My mother's brother and his wife also helped towards the bill. We brought Karel to live with us and he is settling in. My husband has opened his heart and home to my brother and is working with me to help Karel establish healthier habits and to plan for his future. We celebrated Karel's 38th birthday with candles and a lot of hope for a bit of wind in our sails. So much about his long term care is still uncertain. It has not been easy for our children but we're all doing the best we can to build a life that models unconditional love and a commitment to what it means to be a family. And at least, we have the legal documentation needed to make a lot of this happen.

If Karel had been British, or indeed Slovenian, we would have had the same legal document provided to us via an established social service framework. It would have cost less than €100 and would have allowed us to focus more time on preparing our family for this enormous transition. But South Africa is how it is. I just feel for the families grappling with



After a 3-year absence the global community will once again gather to observe the 12 World Down Syndrome Congress at the UN in New York and Geneva.



SEXUALITY WEBINAR

Join us on 16 March at 6pm for a thought provoking and vital webinar for all parents. Email Thando at dssaoffice@icon.co.za to book your spot.



DOWN SYNDROME & SEXUALITY

- When do I start talking about sexuality and how?
- Why is this important?
- Fact & Fiction

Presenter: Tineke Ganz-Malan

SEXUALITY

16 MARCH 2023
18H00 - SAST

Webinar



Send an email to Thando
dssaoffice@icon.co.za
to receive the link
to webinar on Zoom



Down Syndrome South Africa



WDSY 2023
World Down syndrome Day

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With us NOT For us



WITH US NOT FOR US

In celebration of World Down syndrome day we are calling on all organizations, businesses, schools and individuals to help us to create a more inclusive society by including persons with Down syndrome and other intellectual disabilities in discussions and decision-making processes that involve them and their lives.

Let's work together to ensure their voices are not only heard but also listened to and respected.



Rock Your Socks for WDSY

WHAT IS DOWN SYNDROME?

Down syndrome is a genetic disorder as a result of a partial or full extra copy of chromosome 21. It affects all races and all economic groups equally. It is the most common chromosomal disorder occurring in approximately 1 in every 1000 live births.

GET YOUR SUPPORT MERCHANDISE FROM US



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Get your socks for only R50

By buying our WDSY merchandise to support our work, you can help us improve our children and adults to lead richer, more fuller lives. What can be more beautiful than that?

Get your Down syndrome awareness sticker for only R20

TO GET INVOLVED CONTACT:

dssaoffice@icon.co.za 072 652 2377 072 652 2377

www.downsyndrome.org.za



21 March is World Down syndrome day

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Option 2.



Option 3.

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Option 1.



Option 2.



Option 3.

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With us NOT For us



WDSY 2023
World Down syndrome Day

ROCK YOUR SOCKS

For World Down syndrome Day



Buy your sticker for only R20 and Rock your socks this World Down syndrome Day to raise awareness for persons with Down syndrome.



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WDSY 2023
World Down syndrome Day

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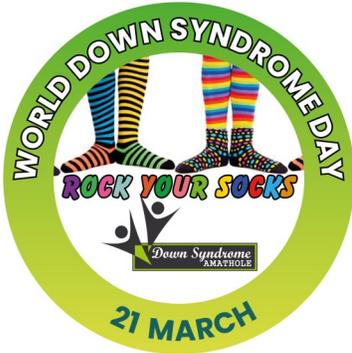
Bookings and payments close 30 March



Upcoming Events Associations

Down Syndrome Association Amathole is planning to do the following for awareness around World Down Syndrome Day.

- * There will be 2 combined awareness mornings during March where DSAA together with Sister Nonnie from CMH will be creating awareness around Down Syndrome and "Congenital Heart Disease (CHD)". This will be taking place at 2 of the local hospitals being – Frere Hospital and Cecilia Makiwane Hospital. One of our self-advocates will be there to talk to the parents on the day as she has had a heart operation as well and this could really inspire the parents to see and hear her talk.
- * We will also be selling our "Odd Socks Stickers" to businesses and schools as a part of our awareness campaign as well as encourage them to wear Odd socks to work and send us pics to share.



* DSAA together with local Autism branch are planning on having a combined awareness walk which will be taking place during March/April (Autism busy awaiting confirmation of the date and details from our local Buffalo City Municipality) as a part of our WSD and Autism awareness campaign.



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Your support makes a difference in the lives of persons with Down syndrome and other intellectual disabilities!

DSSA works each day to create awareness and advocate for the rights of person with Down syndrome and other intellectual disabilities. Throughout March and October we do our best to capitalize on our platform to create as much awareness as possible.

In order to have correct data, we need your stories, we need you to share with us the challenges you have faced, as a parent or as a young adult with Down syndrome or an intellectual disability.

Email your stories to dssa.ned@icon.co.za or whatsapp to 082 478 9741.



WDSD 2023
World Down syndrome Day



With us NOT For us

On World Down Syndrome Day 2023, our global community calls on commitment on "With Us Not for Us"

Our campaign call is to throw the spotlight on:

- **Understanding the right to legal capacity**
- **Good practices in supported decision-making**
- **Easy to understand communication**

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Who we are

Down Syndrome South Africa (DSSA) is a non-profit organisation (NPO 009-415) and was formed in 1986 as the national umbrella body and parent advocacy organisation for 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, developmental delays and their families.