

Autism South Africa's Newsletter

- News from the Community -



Head Office:
Sandy Usswald

We had a bit of a hiccup with our newsletters this year, but I am very pleased to say that we're back up and running! Our official newsletter admin and editor is our very own Dineo Mosiane who joined the A;SA team in May of this year. Dineo is mom to a gorgeous young son with Autism and has a strong project management background. In the future, if there are any news items or events that you would like to share with us and the autism community, please send them for Dineo's attention media@autismsouthafrica.org

This year has been a bit of a whirlwind for the whole team, with my highlight being able to attend a UNICEF meeting regarding Inclusive Education in Paris, France during July.

I need to especially thank the South African Disability Alliance (SADA) for nominating me to represent SADA and the A;SA board for allowing me this opportunity. The outcome of the meeting was a bit disappointing in terms of South Africa as our representatives from the

Department of Basic Education or the Department of Social Development were not in attendance.

The rest of the countries represented, had their Ministers of Education present, so they were able to get to grips with the real, coal-face issues and make principle decisions in regards to inclusive education in their respective countries. So the South African delegation could make recommendations, but nothing tangible.

Another highlight was the start of Diamond families, the South African pilot of the World Health Organisation's Caregiver Skills training. This project is a collaborative project between NGO (Autism South

Africa), Academia (University of Cape Town) and Government (Department of Social Development - DSD). Thanks to funding from DSD we have been able to appoint Dr Liezl Schlebusch as project manager, which has been very exciting. During July we kicked off the project with



bringing together keen stakeholders in the beautiful River Meadow Manor in Centurion. The group was specifically chosen as skilled individuals with diverse backgrounds and occupations, to identify meaningful solutions and strategies to assist families raising children with developmental disabilities in the South African context. For more information about the project, please click [here](#).

Of course my ultimate joy of every year is being able to bring up all the A;SA staff to Joburg for a week of bonding, learning and pampering! This year our pamper day was especially relaxing with a mani, pedi, facial and body massage! We all left feeling very loved and ready for the rest of the year ahead of us!



That was just very few of my highlights for this year! Our upcoming AGM sees our National Executive Committee being elected which is the perfect opportunity to get involved with the strategic management of A;SA. If you are

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interested, please nominate yourself here:
<https://goo.gl/forms/81o8NnjAqllZdDZJ3>

Until Next Time!

Sandy x



Head Office:
Vicky Lamb

Autistic Health Seminar 2018 | A seminar organised by autistic adults for health professionals

The seminar was held at the beautiful Devon Valley Hotel in Stellenbosch. A 3 day seminar, presented by autistic adults and took the direction, not of a traditional workshop, but rather the path of discourse between panellists

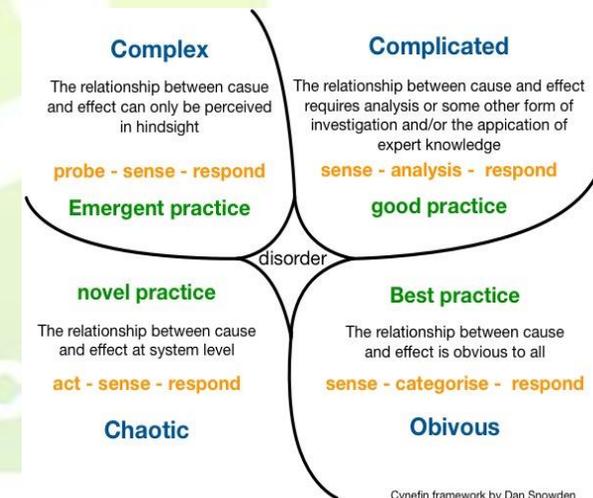
and participants, primarily hosted by Tania Melnyczuk.

There was no set structure to the event - the panellists had an idea of how the days were structured, but the participants did not. Topics that were discussed were varied and did not always concern health, they included; using the terms person with autism vs. autistic; what is autism (how do we define autism); the cynefin framework; emotional regulation; ion channels and ion channel diseases; typical other medical conditions that are sometimes seem with autism, such as POTS and MCAS; talks about sensory overload and what might be contributing to it; non-speaking autistics and their message to the world; and talks about how the brain might work in autistic people; spoons theory, what it is and how it relates back to autism; the long term damage of masking with autistic people; sexuality, gender, being non-binary and what this means for autistic people. Below are just some of what I thought the highlights were from the event.

What is Autism? The first day started out with Tania asking everyone to write down their own definition of autism - this was an anonymous exercise. The idea behind this was to look at how

terminology has pathologised autism, even the good parts. The autistic community does not want their identity to be pathologised. Discussions about different types of autisms came up, that yes it is neurodevelopmental in nature, but that it has different endophenotypes.

Explaining the differences in terminology; person with autism, vs. autistic. This is something I have always thought we should respect. If the autistic community would like to be known as autistic, we need to respect that. It is how they identify, and it is something they are proud of. There are definitely members of the



Cynefin framework by Dan Snowden

community who prefer to be known as person with autism, and that also needs to be respected. But for the majority of the autistic

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community, it is not about celebrating their autism, and it is also not about saying that their autism is better than being neurotypical, but rather that it is equal, and that is different. That it also comes with its own set of challenges, but with that comes novel ways of thinking and seeing the world.

The Cynefin Framework and using it to help with anxiety and meltdowns. We took a slight tangent away from autism after this, to talk about the Cynefin Framework. The Cynefin framework is a way of looking at problems, and then depending on where the problem is, it then looks at how to solve the problem. It puts disorder in the middle, and from the disorder, you can look at it using one of the blocks. Many autistic adults have found this method to be very useful when dealing with their own anxiety, or when dealing with a meltdown - either their own meltdown or another person's meltdown.

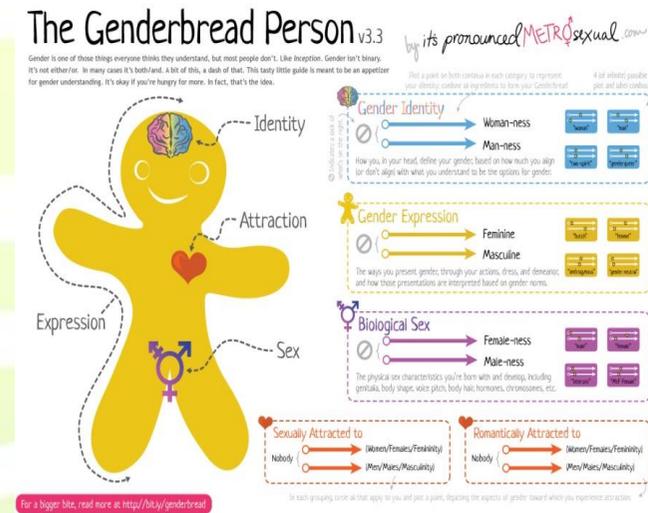
The seminar took quite a windy path, and many of the discussions were somewhat informal. There was a lot of talk around masking in autism, and what the long term effects of that might be. Many of the panellists spoke about this, and how it had resulted in them not being able to make real friends, and about the depression

they had as a result of this, and of not being allowed to be themselves.

Non-verbal vs. non-speaking We moved forward on day two to talk about autistic individuals who cannot speak, but who are intellectually capable. There was quite a bit of talk around the method known as spelling to communicate that is currently being used by some South African therapists to help these individuals with a form of communication. Ultimately, the biggest message here was that we need to ALWAYS presume competence, and if a person does not have a form of communication, we need to ensure that they get a form of communication.

The conversation led to "what is the difference between non-verbal and non-speaking?" Many autistic people who do not use speech as a form of communication say that they are non-speaking - they have the verbal language in their mind, they just can't use it, and often there seems to be the assumption that if someone is non-verbal they are unable to think and process. Non-speaking autistics also speak of the mind-body disconnect - where they know what they want to

say or do, but their body doesn't seem to listen to their brain.



Health Related Issues. On the third day we moved into health related issues that many see with an autism diagnosis. This included Ehlers Danlos Syndrome, POTS (Postural Orthostatic Tachycardia Syndrome) as well as some discussion on PANDAS.

Sexuality and Gender. This was one of the more thought-provoking topics. We all know that autistic children grow up to become autistic adults - but what we often forget is that they too have relationships and choices about their sexual orientation and gender preference. It seems to be that a large proportion of the adult

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autistic community may identify as non-binary, homo-sexual or bisexual. To illustrate all the differences in this aspect, reference was made to the gender-bread person.

There were also discussions around belonging to the BDSM (Bondage, Discipline, Sadism and Masochism) community. Again this was thought provoking, and explanations around this were that for some it gives them sensory input, and for some it helps them to let go of their anxiety.

Conclusion: The last session on the third day was about where do we go to from here.

Unfortunately, I had to leave early to catch my flight back to Jo'burg, however I have asked for feedback from the last session, and will share it once I receive it.

Overall it was an incredibly insightful 3 days - my thinking on autism has completely changed, and I feel that we don't always presume competence even when we know that we should. It's a mind-set, and it's going to take time to change.

Till next time! Vicky 😊



Branch News:
Mpumalanga &
Limpopo
Mary Mooketsi

2018 started with a bang, in the two provinces, we started planning for WAAD events, which took place in the month of April.

In **Limpopo** we had three big events in Capricorn district the event was at Lebomall in Lebowakgomo, it was a collaboration of Lebowakgomo hospital Allied workers and a;sa.

The event was well attended, we had the following department DOH, DOE and a good number of parents and communities.

In Waterberg district the event was at Mahwelereng stadium, the event started with a walk from the nearby police station to the stadium, this attracted a lot of people stopping us asking what it was all about some joining us to the stadium, we had some of the young adults on the spectrum, people from the ECD sector, SAPS, Metro police, families affected and those

who just wanted to hear about about the condition.

For Sekhukhune district the event was at Janefurse Lsen, all six Lsen schools in the district, the circuit manager, district psychology department, community, other disability organisations in the district, St Ritas hospital and the chief of the village where there. It was indeed a successful WAAD for the three districts. For Vhembe and Mopani, we had small awareness later this year, mostly this was in disability centres.

The high light for me in Limpopo is a meeting that I had with the Sansloot head woman, this meeting was organised by one of the families who are of the part of the community who own a small holding farm in Sterkwater, this farm has two beautiful big houses that are not used and they invited me to go and view. In the meeting with Mrs Masenya, I must say an intelligent woman who had a bit of understanding of what ASD is, she even had a bright idea of instead starting on the farm, we could use one of the schools that are not in use in the village. I am sure that this coming year we will have things happening because we are planning an awareness campaign in this chieftainship which is made of

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three big villages and Ms Masenya told me there are many children who are kept at home because parents don't know what's wrong with them and there are facilities for them.

Mpumalanga: We had WAAD in the two districts, Enkangala and Gert Sibande, our usual WAAD collaboration with city of Mbombela took a different turn, we joined Albinism South Africa to do awareness with them because of the killings that of people with Albinism, actually it really worked so well because there is a number of children who have a co-morbid diagnosis of ASD.

In Enkangala district we had WAAD at Witbank hospital, a collaboration of a;sa and the Allied workers at the hospital. This was a great awareness, we had staff of the hospital and patients coming to listen to what we were talking about. We also had an Occupational Therapist demonstrating to parents how sensory integration works. She also cautioned parents about using therapy that has not been researched and proven.

Another WAAD in this district was at Lesedi Pathways this time far North of Mpumalanga province in Bloedfontein. This was a well-

attended event by, community members, home based carers, representatives from the local municipalities.

Issues about children who are kicked out of schools because teachers don't understand them just boggles one's mind.

In Gert Sibande district we also had two WAAD events, the first one it was at Secunda Duck pond, this was awareness with a difference; there were different people doing their own thing, churches talking to people about being saved when they finished telling us about their story we then told them about our story. The high light here was the wedding ceremony, as we were walked around, there comes a little boy in full speed a mother also following full speed in high heels and a beautiful outfit. Trying to help the mom by saying to this little boy, hey where are you running to, answer, nothing hands across his head, mom arrives, oh so you are doing ASD awareness? he is autistic, but I had to relocate to London because here at home because there are no services, perhaps you could come talk to some of the people there". Pleasure is all ours and a mini presentation given to those who came to watch the bride and groom taking photographs.

The next event was at Embamall, where we had parents distributing pamphlets talking to shoppers. We had people who stopped us and asked us why we were blue T-shirts and we would explained to what ASD is.

There was also a report back session about the education, health services and general services for learners and general people with special needs with special needs. We had a lot of disagreement with a number of the departments who wanted us to believe that they were doing something about what we have being complaining to them about. The department of health acknowledged that when it comes to assessment of ASD in the province they still lack behind because they don't have professionals who are able to do diagnosis parents are still send to Gauteng, those who can't afford to bring their children, they stay undiagnosed

Gauteng: In Gauteng with collaboration with City of Joburg, we had a good number of events. We had events in region D, this was ECD practitioners, librarians and high school learners and churches in Soweto. Folks that is all for this time!

Kgotso! Mama Mary.

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Branch News: Northern Cape Elfreda Baartman

Wow! It has been a while and so many things have happened these past few months!

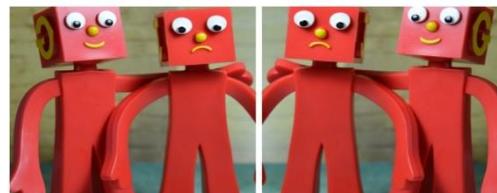
Well, we are in the month of September, and this is my favourite month of the year for a number reasons! ...it is my anniversary and it was Casual day too. I was at Venus Primary school staff decided to dress in school clothes while the learners dressed in casual clothes. This gave a total high to the school day and teaching could not really proceed as normal.



I hosted a workshop at Prof. Z.K. Mathew's hospital on 'Behaviour that challenges'. We had

therapists, a dietician and a dentist present. What a great diverse group it was! They had so many questions. Abby and hubby were there too, so it was interesting for them to meet her. It was very interactive and after all it felt like an interview as they wanted to know so much about Abby and what it is like to raise a child with autism.

As A;SA we also started a pilot initiative which will be implemented in the coming quarter, launching on 10 October 2018 World Mental Health Day.



ASA Buddies

"COZ BULLYING IS A CHOICE!"

AN AUTISM SOUTH AFRICA INITIATIVE



Be a buddy not a bully!

It is all about Bullying! As well as suicide, major mental illnesses, trauma and gender identity. I am so excited about it and I hope it will spread

through the whole of Northern Cape and other provinces.

The year is lying on its back, relaxing so, chill and enjoy the rest of what is left of what was an adrenalin rushing year!

Toodles!! From Elfreda



Branch News: Eastern Cape Antoinette Bruce- Alexander

In July 2016, the Autism SA staff met for a week in Johannesburg and we had the opportunity to meet Balungile Sokhulu - and learn about the Newspaper Recycling project at the Johannesburg School for Autism. As a mom of a 19 year old young man with ASD and manager and co-founder of Autism Sinethemba Early Intervention Centre in East London, and RDO for Eastern Cape for A;SA, I felt this is something I could introduce here in East London for young adults and final year students at the Special Schools with ASD units in our area.

The aim is to teach the young people a skill that they could use in life to be productive and earn

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an income, however small it may be, but it would help them to feel they are contributing in some way to their own wellbeing.

A;SA was instrumental in bringing Lungi to East London to conduct a 4- phase training from September 2016.

They supplied the wooden boards, glue, guillotine and other materials that were needed for the Train the Trainer course. We had a whole classroom full of people, young adults and their parents or caregivers. Some of the schools sent teachers for the training.

We learned to sort then cut the paper, how to roll the paper into a reed-like stick. We receive very generous weekly donations of the newspaper we use for our project from Dispatch Media and Cambridge Methodist Church via a very wonderful man, Rodger Norman! For different colours, we use promotional flyers and adverts that are left over at shops. We never paint anything, the only colour we need comes from the newspapers we use.

Lungi returned every month for the next phase of training. We learned all the processes

needed to manufacture the bags, earrings and other unique sale-able items.

After we completed the course, we each received our Trainer certificates, Lungi handed over the project to us to run as our own!!

It is very good to see how parent and child work together. If the parent or caregivers are not 100% on board with our program, the child will not learn and grow in the skills we are trying to teach.

This group also serves as a social get together for the young people and a support group for the parents who may face similar issues at home and school. The youngsters are very aware of each other and keep a close eye on their friends". We create a better life for our young people, they build a lot of confidence because they have new skills that they can earn money from.

We are using a lot of hand gestures and hand-over-hand assistance - mostly when we are teaching new skills - with those who cannot verbally communicate and a few MAKATON signs

are used as well.



The pride is very obvious when the young person complete the items they are busy with, or as in the case of Adrian, he can roll 332 sticks in 2 minutes, his new personal best. It provides a sense of accomplishment and completion of task. A task has a clear beginning to end, where they put money in their bank account or pocket. We have had a few successful market days where the young people sold the items they made.

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We encourage them to make as many items as possible, when sold, 90% of the money goes to them, 10% comes to the project to buy more materials.

As a mom of a child with ASD, my focus changes as he gets older. When he was 4, I started Autism Sinethemba, when he was in Primary School, I became the SGB Chairperson for his school for 7 years, now that he is a young adult, I needed to find something he could do as an adult to be productive and earn money, and this project is it! Many parents feel the same way that is why we have had a successful two years. We have the commitment of parents who have the same need as I do and the same vision for their young fellows.

Many Thanks! From Ant.



**Branch News:
KwaZulu Natal**

Rosemary Shezi

Mass Community Autism Awareness was held at Buffelsdraai Sports Grounds outside Verulam on Saturday 30 June 2018. It was a huge success. A big thank you; to Veronica Mtshali for co-ordinating, planning and attending meetings up until the awareness event. Thank you EThekweni Municipality Waste Management for providing the stage truck with the sound system and beautiful music. Thank you to all the sponsors and our partners, Metro police, SAPS Support, Tito Bus service for providing busses to ferry the community to and from the event. The volunteers, caterers, Ward 59 committee and councillor, ward 59 War room and Ethekeeni Department of Health in partnering with us and providing their Community Care givers to act as marshals during the event.

We had a successful Autism awareness and information sharing session and celebration at Pholela special school. In attendance, we were blessed by the presence of local traditional and political leadership and the local chief.

We had a successful 67 minutes Mandela day campaign at Ethekeeni Ward 12 in partnership with Ethekeeni Municipality disability forum. Activities included clean up at Sonke Disability Care Center and handing over of walking sticks, walking frame and a bed donation to one family. I partnered with the Dept. of health and rehabilitation services; in a door to door campaign on a disability needs assessment to identify families, with learners not attending school.

Khalipha special school hosted a Differentiated Caps Curriculum Seminar for parents and disability organizations; to highlight how learners with autism and other disabilities will benefit. It was a successful occasion, hosted by Mrs Mbokazi, the principal and her school team.

Ethekeeni Municipality Vulnerable groups' office hosted a Business empowerment and motivation day in celebration of women with disability and mothers of children with disabilities on 25 August 2018. The highlight of the event was the Madiba song and a poem by Nontambo Ngcobo from Ningizimu special school, she has Autism. Viva Nontando!

Nginyabonga From Mama Rose.

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Branch News: Free State

Selinah Jele

We established a project empowering lower resourced families of children on ASD.

This collaborative project with Department of Education began out of a desire to spread our support. In 2018, we welcome a wonderful, creative approach and hard-working year.

Currently the Department of Health provides coaching to families, it requires parents or caregivers to provide appropriate coaching to their child at home.

The empowerment of Parents will be an annual project across the Free State that offers training to parents that have Autistic children.

This program guides parents in implementing skills around decreasing behaviour that is challenging at home.

We are also fortunate to be working with Child Welfare and Lifeline in recruiting new families.

Elizabeth Rose hospital offers medical assistance and will look after the medical concerns of the child and family; while Autism South Africa and Lifeline will be looking after the wellbeing of the parents and offer emotional support, should they require it. We feel so fortunate to have the opportunity as an

organisation, to be participating in such a holistic support service in the Free State 2018 season and we are hopeful that the office continues to grow and be inspired by our wonderful and eager families.

Bye for now! From Selinah



Branch News: North West

Dineo Mosiane

Joining the team

I am truly grateful to God for having allowed that I become part of this hardworking, knowledgeable, humble, dedicated and passionate AutismSA team.

In 2014, my son and I (then 3years) visited the A; SA office for the Assessment which gave me the diagnosis and way-forward I needed. Little did I know that one day I would be Regional Development Officer and have to carry out the same duties as the people who had found me helpless and distraught as a mom and assisted in my son's journey.

North West Province

After being appointed, I switched into research mode, to understand the demographics of my province and to ensure that, in my quest, no village or town is left untouched by my A; SA

work. Only to realize that I myself didn't know NW as well as I thought.

-Four large districts, consisting of 386 wards, - ranked 7th largest in population SA (CENSUS 2011) with estimate of 3,509,953 people,- 6th in area span of 104,882 km³, -Languages being Tswana-63%, Afrikaans-9%, Sotho, Xhosa and Tsonga covering the remaining 28%.

-How many LSEN (Learners with Special Education Needs) schools in NW? 37!

-How many are for Intellectual disability and how many have our Autistic learners? *For me to find out!*

-How many Mainstream primary schools and Secondary Schools? What about our Autistic learners there?

-How many ECD Centers, Privately owned centre and schools?

All these trivial facts you may think: Was I trying to scare myself out of the job or what? The answer is a huge NO!! Just like the autism brain, our minds work in different ways, that had to be my starting point, and yes Sandy I was "freaking out" at one point. However. after meeting everyone in the team, training and orientation, receiving the necessary tools, I realized that it can be done. As with every province where our RDO's work, just taking sizeable chunks with every bite; One day at a time, touching lives:

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Eventually A;SA vision will be realized.

"A;SA aspires to achieve a society in which all people on the autism spectrum enjoy all rights and opportunities to meet their needs and fulfil their potentials, throughout their lives, as equal members of their families and communities."

In Mahikeng, Casual day, Friday 7th September , was celebrated with four centers coming together for an event with theme "Be an Everyday hero".

Oratile Semunza Disability centre, Kgaratlho Center for the Blind, Signal Hill Disabled centre and Feel at home Disability Care.

Dept. of Social Development co-ordinated the planning, and we had guest speakers living with disability, employed by Dept. of Home Affairs and Health, who motivated and taught audiences on their life experiences.

I presented 'What is Autism?' and an educator, Lerato presented 'What is Albinism?' ...It was a fun-filled day for all present, including beneficiaries of these centers, with performances from singing, to traditional dance and poetry. We hope it will be an annual event featuring and exposing more people living and working in the Disability Community.

Kealeboga!!! From Dineo

**Feature
Articles**

**From
The Editorial
Team**

Stephan R "A Night Out"

Autism South Africa and STEPHAN R presented "A Night Out" - a musical production that took you on a global journey to some of the world's famous musical venues.

STEPHAN R and Night Angel performed a kaleidoscope of music featuring some of South Africa's best musicians and supported by the Unisa choir as well as Margie Houbert dancers.



Thank you to all who supported this event! We hope you enjoyed it as much as we did. For those of you who didn't, below is some information about Stephan.

At the age of ten, Stephan (now a 15-year-old musician with Autism) expressed the wish to use his musical talents to assist those in need.

Aligned with his vision, Stephan, Night Angel together with his best friend, Lebogang Mokoena (a 15-year-old voice-over artist with ADHD) staged this exciting musical production to benefit the charity of their choice, being Autism South Africa.

Source: Vicky Lamb

Casual Day, Friday 7 September 2018



22 Years ago; **The National Council of and for Persons with Disabilities (NCPD)**; conceptualised and started the Casual Day campaign in South Africa. With its footprint throughout South Africa the NCPD is supported by 9 affiliate provincial structures called the Association for Persons with Disabilities (APDs)

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and is seen as one of the leading non-profit organisations in the disability sector of South Africa.

At a national level the NCPD has 5 focus areas which includes providing assistive devices to persons with disabilities, providing sensitisation and disability equity training to potential employers, providing universal access scans and audits, promoting an awareness of the various challenges faced by persons with disabilities in South Africa and advocating for the rights of persons with disabilities for full integration and inclusion into society. On a provincial and local level the APDs deliver services in the communities that they operate in to support and represent persons with disabilities.

Casual Day is run in partnership with its 14 national beneficiary organisations who receive a portion of the funds to run their organisations. They are:

- ★ The National Council of and for Persons with Disabilities
- ★ South African National Council for the Blind
- ★ South African Federation for Mental Health
- ★ Deaf Federation of South Africa
- ★ Autism South Africa
- ★ National Association for Persons with Cerebral Palsy
- ★ National Institute for the Deaf
- ★ Alzheimer's South Africa

- ★ QuadPara Association of South Africa
 - ★ Transoranje Institute for Special Education
 - ★ Blind SA
 - ★ Cheshire Homes SA
 - ★ Muscular Dystrophy Foundation of South Africa (MDFSA)
 - ★ South African Disability Alliance
- For more information

visit www.ncppdsa.org.za or follow us on at www.facebook.com/disabilities.sa

Source: www.casualday.co.za

A special thank you to everyone who participated this year, by purchasing and selling stickers and other casual day items!!!

SPECIAL THANKS:



Thank you **RAM HAND-TO-HAND COURIERS** for always assisting us and for distributing the stickers countrywide for us!

Demanding better education for children with disabilities

In January 2018, the Department of Education estimated that about 500 000 children with disabilities had no school to attend, with many placed on waiting lists for special schools for up to five years.

While children with disabilities by law are allowed to go to schools of their choice, only 120 000 children attend public schools with their peers without disabilities. Disability organizations are now taking a stand against the Department of Education. Autism South Africa, National Council of persons living with disabilities and Down Syndrome South Africa are the complainants in a legal action against the department.

They are being represented by The Center for Child Law. Sandy Usswald, Director for Autism South Africa notes: "We know from recent media reports that there are 500 000 children with disabilities out of school and this is an immediately realisable right that is being denied to our children. We are trying to collect the names and stories of as many families as possible so that we can represent them in this case." The organizations are calling on parents of children with disabilities to complete a short survey to share their story. For more information about the case, contact AUTISM South Africa directly at director@autismsouthafrica.org

Copied directly from Source:

<https://www.rollinginspiration.co.za/demanding-better-education-for-children-with-disabilities/>

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Interesting Events and Dates:

- **Mental Health Awareness Week: 10 October 2018.**

October is also Mental Health Awareness month as well as Attention Deficit Hyperactivity Disorder (ADHD) Month. (*S.A National Health Calender*)

- **Health care innovation Summit Africa 2018 - 17 and 18 October 2018** at Gallagher Convention Center, Johannesburg, S.A
- **1st Mental Health Symposium for civil Society** by the African Umbrella for Mental Health Care. **29 - 30 October 2018** in Gaborone, Botswana.

"What is happening in the rest of S.A?"

Send your news to:

media@autismsouthafrica.org

Hope you enjoyed all our news: Next issue Volume 2 Issue 2 will be out 25th November 2018.

Volume 2 Issue 1: October 2018

To Share your news please email director@autismsouthafrica.org ||| www.aut2know.co.za ||| Office: 011 484 9909 ||| fb: AutismSouthAfrica