COMMUNICATION OPTIONS FOR THE OFFICES OF AUTISM SOUTH AFRICA

Ground Floor, Children’s Memorial Institute
Up the hill behind the BP Garage
Gate 13, Cnr Joubert Street Ext and Empire Road
Braamfontein, 2001, South Africa
Tel: +27 11 484 9909
Fax: +27 11 484 3171
info@autismsouthafrica.org

Please regularly check our web page
www.autismsouthafrica.org
for the latest news, upcoming events, electronic brochures, etc.
Autism South Africa can also be found on Facebook (look for the above a;sa logo)
We would love to see you join us, benefit from the interactions on this Facebook site, as well as possibly contribute to the Discussions?

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Editors Letter

Hello All and Welcome to Edition 16

A big thank you to everyone who submitted superb stories and articles. We were so overwhelmed with material that I must apologise to those of you who’s contributions we were unfortunately not able, due to space constraints, to be published in this edition. If you thought about sending material through but decided against it for any reason, please do so next time. Please consider sending short letters and articles (maximum of 500 words per article) and preferably in a word document. Please also send a photo of yourself or one relevant to the article.

If you come across any interesting articles that you feel will benefit our readers, please feel free to forward them to us.

Inbetween aut;talk’s you can browse our web page for news on upcoming events as well as become a fan on our Facebook or Twitter pages, just look out for the ‘a;sa’ logo. We update the sites with pictures and info on a regular basis.

Have a wonderful summer holiday and if you are travelling, go well and return safely. We look forward to hearing about your projects and receiving your articles for the next edition of aut;talk.

The deadline for content for the next aut;talk is the end of January 2011.

SNAP Training Dates for 2011

Basic SNAP Training Program
31 Jan - 11 Feb 2011
R3,320.00

1 Day Teacher Training
25 Feb 2011
R 450.00

1 Day Professionals Training
11 March 2011
R 675.00

Facilitator’s Course
4 - 8 April 2011
R1,620.00

“If you start using a medication in a person with autism, you should see an obvious improvement in behavior in a short period of time. If you do not see an obvious improvement, they probably should not be taking the stuff.

It is that simple.”

Temple Grandin
Due to the generous funding from the National Lottery Board, Autism South Africa, the national body for people with autism is pleased to announce two new staff members; Lulama Sikakane who is the National Development Officer and Trishana Soni who is Regional Development Officer: Autism South Africa Greater Johannesburg Branch. Autism South Africa has always focused on transformation and de-centralisation of services. This move serves as a platform to enhance the growing demand in remote areas to further conduct training workshops and upskill educators. This will also decrease the backlog in many schools that cater for children with autism.

According to Jill Stacey, National Director of Autism South Africa, “The main focus for us has always been to assist around the country and appointing two more officers will add value and make us go an extra mile in training educators an achieving our objectives”

CONTACT PERSON:
Jill Stacey
National Director
Autism South Africa
Tel: 011 484 9909 * Fax: 011 484 3171 * Cell: 071 885 9286
jill@autismsouthafrica.org * www.autismsouthafrica.org

I am excited and honoured to be part of a team that is Championing the cause of persons and families of a Spectrum Disorder such as Autism. Being a mother is my most rewarding and challenging of life experiences requiring lifelong learning in the journey through life. I learn from my son Avathar everyday something new about life, about him and mostly about me. I have a passion for learning, education, training and development. I was born and grew up in Kwa-Zulu Natal. I moved to Johannesburg and have made it my home for 17 years.

I completed a Bachelor of Arts Degree at the University of Kwa-Zulu Natal, an Honours Degree in Clinical Psychology at the Nelson Mandela Metropolitan University and a Higher Diploma in Education at WITS. I began teaching 12-18 year olds and then joined the Department of Labour as a Vocational Counsellor. I worked at the Department also as Labour Training Advisor, Assistant Director Training, Development and Performance Management and Assistant Director Human Resources. I completed a Diploma in Remedial Education, cum laude at the University of Johannesburg and a Masters Degree in Adult Education and Training. I worked in the NGO sector as Deputy Director Education Projects. I consulted to various Government, non-government and corporate enterprises for 3 years in education, training and development and strategic planning.

Besides South Africa I have worked in Namibia, Zimbabwe, and Swaziland and as a volunteer in Australia with mother and child refugees. I was Head: Training at BCX for 3 years. I completed the Higher Diploma in HIV/AIDS in the Workplace through the University of Stellenbosch. I completed the BCX Management Development Programme at GIBS, with distinction and came 2nd in the class of 2007.

I am currently studying towards a Masters Degree in Educational Psychology and am completing a minor dissertation in Community Psychology, conducting research on Children with Autism and their families at Autism South Africa. I want to complete a PhD in the long term that explores the plight and possibilities for Autistic children and their families in the South African context.

In the short while I have already spent as Greater Johannesburg Regional Development officer I am cognisant of the challenges faced by autistic children and adults and by families and care-givers of autistic children and adults. I look forward to engaging autism spectrum disorders children and adults and their families in meaningful ways that will improve their lives and enrich mine.

Love and Light..........Trishana
Autism South Africa hosts a Screening Clinic once a month on a Saturday for children between the ages of 2 and 14 years old to establish or eliminate the possibility that the child has an autism spectrum disorder. The assessment takes place at the offices of a;sa, in Gauteng and is done voluntarily by professionals in the field e.g. doctors, therapist and educators.

Procedure by which to have your child assessed by the screening clinic at Autism South Africa: -
- First contact a;sa for a screening application form (you will at the same time be asked a few questions about your child and history e.g. age, behaviour, school, who referred you, and has your child been to a neurological clinic / neurologist / doctor, if you have not taken your child a;sa will refer you to one)
- The application form is to be completed by the parents or primary caregiver of the child and returned to a;sa
- Together with medical, therapy, and school reports of your child
- The returned report will be reviewed by the doctors which can take up to two weeks
- If the doctor suspects the child has autism, a;sa will contact the parent to schedule an appointment for the screening clinic
- When a full analysis of the screening is complete a report with the results will be forwarded to the parents and recommendations for the way forward will be discussed

We at Autism South Africa would like to take this opportunity to thank these professionals: Professor Lorna Jacklin, Dr. Linda Kelly, Dr. Heather Thomson, Dr. Gillian de Vos, the therapists and various educators for donating their time, efforts, dedication and their expertise which is extremely valuable to mapping a beneficial intervention strategy for the parents to take away after their appointment at the clinic.

Assessment / Screening Clinic Team

Our brilliant clinic team, thanks guys for doing a great job!

Parents can occupy their children with toys and books while they wait to see the doctors and therapists.

The observation room is equipped with live audio visual feed used for training at the clinics.

Congratulations to the following 6 people who at the Annual General Meeting of Autism South Africa on 11th September 2010 were elected to serve a 2-year term on the National Executive Committee.

**Mrs Petra Dillmann**

**Dr David Griessel**
Principal Specialist – Dept of Paediatrics and Child health University of the Free State. Heavily involved with establishing services for people with autism in Bloemfontein.

**Mrs Christine Koudstaal**
Principal of Unica School in Pretoria for 28 years, Chairman of the ASA Out-Reach Education and Training Committee. Present NEC member Committee Member of the Association for Autism (Pretoria).

**Mr Thabo Leshilo**
Father of a son with autism. Past NEC member (1 year). Mr Leshilo has just returned from the United States, where he spent 10 months completing a Nieman Fellowship in Journalism at Harvard University. Mr Leshilo is presently the Public Editor (Reader’s Advocate) at Avusa Media.

**Nomsa Masoka**
Mother of a son with autism. Qualified Speech therapist and Audiologist.

**Mr Paul Pratt**
The Concord Trust donated R300 000 of unrestricted funds.

The Robert Niven Trust donated R50 000 for the outreach education and training programme.

Autism South Africa was one of 56 charities to receive R80 000 from the NSL/Telkom Charity Cup.

Due to The DG Murray Trust providing R156 000, Autism South Africa has launched 12 new brochures, the content for these brochures was supplied by the UK National Autistic Society (NAS).

Toys R Us, South Africa have entered into a partnership with Autism South Africa and pledged R250 000 over a two year period. In 2011 Toys R Us will be identifying a selection of toys that, when sold, a percentage of the sale, will be donated to Autism South Africa.

AngloGold Ashanti has donated R40 000 to develop an Outreach Awareness Programme in Soweto. Posters and brochures will be distributed to all clinics. As a result of funding received from the NLDTF, Autism-specific educational material will be donated to schools that have enrolled learners with autism.

ApexHi Fund has provided R80 000 towards regional development.

We received R20 000 from both BHP Billiton and Putco.

Through the “The Trust”, Autism South Africa received R 45 000 from the sale of the Bafana Bafana World Cup bracelets.

Medi-Clinic donated R55 000 towards the Outreach Education and Training Programme.

Willowton Oil Group is celebrating their 40th anniversary and is providing Autism South Africa and another 39 charities with R100 000 each.

The Autism South Africa Golf Day in July raised R 45 000 and in November our “Comedy for Autism” event at Parker’s Comedy and Jive, Montecasino, brought in R17 500.

Jimmy van der Walt, at the “Pin and Putter” Pub & Restaurants remains a strong supporter and during the winter period he hosted a Potjiekos Competition and raised R2 400 for Autism South Africa.

September 2010 was a historic month for ASA; we received our largest single donation ever...... R1 410 00 from the National Lottery Distribution Trust Fund (NLDTF).
Autism SA expands
written by The Media-teers

The Lads tell us their experience...

Autism South Africa (a;sa) has dedicated itself in embarking on a journey to increase and create awareness about autism, assisting individuals who are directly and indirectly affected by autism by any means necessary.

During the course of these past few months Autism South Africa has expanded its family by engaging the services of three young University students who were absolutely oblivious about what autism entails and how delicate of a matter it is to those who are familiar with it.

Edwin Chabangu, Nhlanhla Kubeka and Kgotso Nkhumise are third-year students currently studying Public Relations and Communication at the University of Johannesburg Bunting Road Campus. These three young men, who frequently refer to themselves as the "Media-teers", were taken on by Autism South Africa to assist Jill Stacey and her team to improve the awareness of autism not only locally but also nationally.

The Media-teers have experienced several emotions while working at Autism South Africa, both good and bad, but it has definitely been a worthy experience that has given them a chance to not only make their mark in the Public Relations industry but also give back to people who are affected by autism.

This is what each Media-teer has to say about their experiences whilst working at Autism South Africa:

Edwin Chabangu

If there ever was a time where I had to explain the word fun, than my experiential training at a;sa was it, infact fun is an understatement, I had a blast.

Autism South Africa is an organisation that has not only taught me how to work constructively, but most importantly to perfect the art of paying attention to detail, the latter was inevitable as I was surrounded by seniors who make experience seem like a sunday walk in the park.

The people who work at a;sa are like pioneers of a solid craft because they have provided me with a platform and foundation which is not only solid but unshakable. I’ve had moments of difficulty, when the journey seemed like a trackless jungle of indecision, I always turned to my seniors for assistance.

Personally I believe that the relationships you build today might determine your tomorrow, this one is directed to the Media-teers, Nhlanhla, and Kgotso, who I not only study with but also work with, my time with you has not only been an honour but shall linger in my mind for all times sake, and finally to the dream of living life large we shall come back to a;sa as future CEO’s and continue doing what we do best in helping others understand the concept of autism, because our professional attachment to a;sa has become personal as well.

My time at a;sa, without a shadow of a doubt, has been an experience that shall linger in my mind for all times. I have learned more about PR and Communication than I initially thought I would, therefore it is fitting to say that the future seems too bright with the platform I have acquiried over the past.

When the industry calls I shall wear my heart on my sleeve and stand tall for a;sa has prepared me well.

Nhlanhla Kubeka

What has been the ultimate cause at Autism South Africa is being granted the opportunity to learn from individuals who hold high integrity and workmanship in their regard. This relates to making a difference to individuals who can't foster to do it themselves and Autism South Africa provides that opportunity to those individuals. Being with a team that strives for excellence, seek productivity and naturally humble people has taught me to persevere, to show character, be proud and stand firm on the practice of making a difference.

Working for a NPO has taught me to live within my means and a;sa has sharpened and enhanced my communication skills. I have built a foundation that will propel me to be an expert in the communication field in the future.

I'm very honoured and fortunate to be given such opportunity, a learning experience that has and will continue endure good prospect for me.

Kgotso Nkhumise

At first I was not really keen on working, I was more in tune with completing my studies, obtaining my National Diploma and then looking for a high-paying job that will see me living the life of a Rockstar without a single care in the world.
Two silver Corsas with same number? Go figure...
written by Gillian McAinsh 2010/05/06

When someone tells you another car – the same make and colour as yours – is driving round with the same number plate in the same suburb you might just be tempted to ignore him. After all, your number plate is like your finger print, no one else should have it, right? Wrong ... because if that person is autistic handyman Michael MacGregor, you listen.

A general assistant at Quest School for Autistic Learners in Port Elizabeth, MacGregor has a near photographic memory and the car in question was my silver grey Opel Corsa. He spotted another, earlier model Corsa, with the exact numbers, FDK 175 EC, a few weeks ago.

As an honorary advisory member of Autism South Africa, Michael is aware of his condition but realises that what sets him apart also is, in his case, a gift. “You can read me like a computer,” he said, reeling off an impressive memory for figures and letters. “I’ve always had a special gift with the alphabet and numbers, but I’m no mathematician. In a sense it’s a photographic memory.” MacGregor’s condition, autism, means he has difficulty with social interaction and communication. Aged 53, he has never married and lives with his parents in the top end of Walmer on number 6A Villiers Road. Despite a flair for the bass guitar, a love of classical music and Dr Seuss, he admits he can be obsessive and resistant to changes in his routine.

“My greatest achievement is to be able to function in society. It is very important to be able to serve society.” MacGregor does not only remember registration plates but also phone numbers and his phenomenal memory dates back to his childhood, growing up in New Zealand. “I remember a number plate in the late 1960s of a Ford Zephyr Special, CT 6361.”

MacGregor’s repeated inquiries about my car eventually spurred me to call the Port Elizabeth traffic department. “This is not good,” said a Mrs Fourie, confirming that doubling up should not happen. Perhaps, she suggested, the number plate manufacturers had made a mistake with the plate, while the licence registration was correct? This would mean that fines for the one would have to be paid for by the other – I liked this theory as FDK 175 EC already has a speeding fine. Hey, perhaps my number was wrong, and the fine belonged to the “twin” Corsa?

But how to find this other car? It would be like looking for a needle in a haystack, or one car in a city of hundreds of thousands. Once again, MacGregor the human computer came to the rescue because he knew exactly where to find it. I drove to where he suggested and discovered that its disc indeed did not match its plates while mine did. The driver, JP Dyer, was oblivious to the error. Soon afterwards MacGregor stopped me at the school gate to report Dyer had replaced his plates to match his disc. Shame about the speeding fine though ...

Good Luck on the road ahead Lads, may you have enriched lives full of excitement and adventure!

The Media-teers.

Then my world reached a stand still when we were told at University that it is a prerequisite to undertake Experiential Learning in order to successfully complete our studies and graduate the following year.

I was sceptical because I had no work experience whatsoever and finding a job was a futile mission till fate presented itself in an unexpected phone call.

I received a telephone call from my fellow classmate and PR intern at the University of Johannesburg that an organisation called Autism South Africa is willing to employ me due to my credentials displayed on my Curriculum Vitae. I was so ecstatic yet awfully nervous of the opportunity that had presented itself in the form of Autism South Africa.

On the day of the interview I prepared my best formal attire, sharpened my charisma and headed to Autism South Africa. I met Marleen Gregorio who made me feel right at home and finally I met the "head honcho" Jill Stacey who seemed rather intimidating but to my surprise she welcomed me with open arms and made me look forward to working for the first time in my life, to add onto that I signed my first contract ever, WHAT A THRILL!

My experiences at Autism South Africa have been the best ever, due to the fact that I have learned more about autism and what it entails, I have also managed to adapt to the working environment and further harness my skills as a PR and Communication Practitioner.

In essence I would like to show my appreciation to my a:sa colleagues: Jill Stacey, Claudia Ceresa, Louise Taylor and Marleen Gregorio, for the constant guidance and support they have given us throughout these past couple of months as we venture into the world of the unknown and to my fellow Media-teers, Nhlanhla and Edwin, may our paths be paved with good intentions thus allowing us to prosper and gradually reach the pillar of success.

We thank you all for this wonderful opportunity and God bless.

The Media-teers.

Two silver Corsas with same number plate.
Q + A to the National Director of Autism South Africa  
by the Media-teers

What actions have been taken to ensure the distribution of information?
Over the past 3 years we have translated one of our brochures named “Autism – Practical Aspects” into isiXhosa, isiZulu, Setswana, Sesotho, Sepedi and Afrikaans. Autism South Africa has a web site that is regularly updated with relevant information (www.autismsouthafrica.org), as well as an email database of approximately 2500 people who at least once a week, receive relevant information through this route. Autism South Africa has a Facebook site with close to 2 000 fans and we are updating our fax, SMS and postal database to enhance information distribution to those people without Internet access.

Close to 5000 hard copies of our comprehensive 50-page newsletter, aut;talk, created by Autism South Africa on a 6 monthly basis are distributed to parents and relevant professionals, schools and centres.

The UK National Autistic Society and Autism South Africa signed a Memorandum of Understanding last year, what exactly is incorporated under this MOU?
Autism South Africa needed to expand its range of brochures and as a result of my fairly regular contact with the UK National Autistic Society and respect for their material, I approached them, instead of “re-writing” the wheel, to have permission to utilise a selection of their material. This was agreed to with immediate effect and they then sent us the content of their 12 most popular brochures for which we are eternally grateful.

As a result of an exceptionally generous donation from the D G Murray Trust, we were able to adapt and illustrate this range of brochures and print 2000 copies of each, that are now available through the offices of Autism South Africa.

7. Why does Chris do that? By Tony Attwood.
11. The sensory world of the autistic spectrum: a greater understanding. By Kate Wilkes.

(For a complete publications catalogue from the UK National Autistic Society or to order on line see the NAS website www.autism.org.uk/pubs)

Toys R Us donated R 62 500 to turn these brochures into a colour format, with The Hollard Insurance Corporation and Pallet Supply Company provided vital funding to cover the shortfall for this milestone project.

The National Lottery Distribution Trust Fund(NLDTF) has provided increasing support to Autism South Africa over the years. Can you highlight the main areas this funding has impacted upon?
The NLDTF launched and subsequently further developed two of the main programmes undertaken by Autism South Africa; the nationwide Out-Reach Education and Training Programme, as well as the development of the first-ever provincial branches of Autism South Africa; 6 of which are being established at present:

Autism South Africa Greater Johannesburg branch  
Autism South Africa Free State and Northern Cape branch  
Autism South Africa Eastern Cape branch  
Autism South Africa KwaZulu-Natal branch  
Autism South Africa North West branch  
Autism South Africa Mpumalanga and Limpopo branch

Another massive step in the right direction is that part of funding allocation from the NLDTF is to appoint a full-time National Educator, whose sole purpose will be to facilitate Information Sessions around the country at schools, colleges, clinics and related services as identified by the Regional Development Officers. De-centralisation of services is essential to ensure that we improve the accessibility and affordability of services for all people with autism, especially those who live in the lower-resourced areas.
The phenomenal support from the National Lottery Distribution Trust Fund over the years has been a major factor in the growth of Autism South Africa’s services, but it is also essential to acknowledge all our benefactors who have contributed to these two programmes, as well as the tireless professionals, who have volunteered many hours towards the expansion and improvement of our outreach services.

**Toys R Us has recently committed to a two-year partnership with Autism South Africa, how will this assist children with autism and their families?**

When Issy Zimmerman, Director of Toys R Us South Africa, told Autism South Africa that Toys R Us would be donating R250 000 over a two year period, Autism South Africa were ecstatic! In addition, Issy informed us that they will be putting specific focus on enhancing the awareness of autism through their branding and promotional channels. If this was not enough, Autism South Africa learnt that in 2011 Toys R Us will launch a highly informative product booklet for their stores, highlighting products that will be beneficial to enhancing communication skills, fine motor skills, cognitive development, etc. What a truly outstanding pledge to not only assist children with autism or special needs, but obviously this unique approach to guide and assist parents with their decision to purchase toys to benefit developmental progress for all children.

**Ernie and Liesl Els as a result of their son Ben having autism, are very involved in services in America, but are they assisting you in any way in South Africa?**

Most definitely! In December 2008 The Els for Autism Foundation hosted a golf day in Somerset West where close to a R1 000 000 was raised and distributed to Autism–related services around South Africa. In 2011 this foundation will be sponsoring web-based learning platforms designed by Re-Think Autism (USA). The first site will be at the offices of Autism South Africa and if this approach proves to be beneficial in South Africa, then additional terminals will be established around the country.

**What has been the key feature or outcome for the regular Information Sessions and Workshops conducted by Autism South Africa?**

Minimal information on autism is included in the curriculum for the training of teachers, therapists, medical and para-medical professionals. Our workshops therefore are chiefly aimed at increasing knowledge on autism amongst the relevant professional fields, as well as to provide basic guidelines on beneficial approaches when working with a child with autism. After the workshops we encourage professionals to then attend more in depth workshops or receive training on specific aspects of autism intervention.

**What are your plans for next year?**

The work undertaken by the staff of Autism South Africa in 2011 will chiefly be to establish, support, monitor and ensure sustainability of the new provincial branches of Autism South Africa. For the first quarter of 2011 the newly appointed Provincial Development Officers will be reaching out to the previously isolated families with children or adults with autism, special-need schools, as well as the Primary-Health clinics and hospitals, to establish their needs. The information gleaned at this grassroot level will provide the operating guidelines for the provincial offices and a directive for the national educator as to how to prioritise the distribution of information and resources that desperately need to be delivered to varying communities across the country.

**Do parents find it relatively easy to take their child to shopping malls, restaurants etc?**

60% of the information humans take in is visual and because autism does not manifest with any external signs, quite understandably many people not involved in the field of autism cannot fully conceptualise the far-reaching ramifications of autism. Many “symptoms” of autism are reactionary behaviours and therefore often people look at this seemingly “normal” child and think they are behaving badly. The average member of public does not realise that the child that is screaming, fighting against his parents’ grasp or has dropped to the floor crying with his hands over his ears is actually extremely anxious and a victim of sensory bombardment like most of us will never experience. The UK National Autistic Society has a slogan that they place on shirts for children with autism and it says “I am not naughty, I have autism!” I would like the public when they are judging a child who seems to be having an inappropriate “temper tantrum” to bear in mind that possibly this child has autism and is extremely anxious and confused by the surrounds and that the parents need support not criticism.

**You have a 25 year old son with autism has it become easier for Michael and you as a parent as he has grown up into a young man?**

No, not as far as my son is concerned, as he has autism plus a significant degree of intellectual impairment, thus the challenges do not really get less as such, they just change!

**Do you wish that Michael’s autism and intellectual impairment would disappear and that Michael could be “Normal”?**

I suppose for his sake, when I see what he has to go through, yes, but at the same, I would miss my “Autistic Michael” so much. Michael has taught me a great deal, his condition has meant that I have met many truly wonderful people I would never had met, I have had experiences I would never have had and I also believe he has given me a much better perspective on life.
In February 2010 I was invited to present at the Autism South Africa Durban workshop. This article is an edited version of that presentation. I would like to share my experience as a mother working with a method of intervention called Relationship Development Intervention, or RDI as it is commonly known. I am not an RDI Consultant and I am not being paid to write this! I am just a mum trying to weave RDI into our daily lives. I am the mother of Nick, an 11 year old boy with autism and a number of other co-occurring conditions, which makes him severely challenged. In a nutshell RDI is a developmental intervention and was founded by Dr Steven Gutstein, a US based psychologist. It is an intervention that addresses the core deficits of autism and it is all based on typical social, emotional and communication development. Parents are taught how to re-establish their relationship with their child and how to guide their child through the developmental steps and stages that they have missed. These aspects need to be in place to provide a foundation on which to build meaningful relevant knowledge.

Basically, the way RDI is implemented is that the family works with the child under the guidance of an experienced consultant. We have been involved with RDI for around four years and we were under the guidance of a consultant for a period of that time. Our consultant came from the States in May 2007 to consult with a group of Durban families. Obviously to get him to come here wasn’t cheap. As well as the assessment cost we also had to pay for his flights and meals. Around the time of his visit, the Connection Centre (the home of RDI) introduced an online learning support system for parents and consultants. I had the opportunity to use this facility and I loved it. They had parent objectives that needed to be worked through before a parent could be assigned child objectives. I was also able to access the child objectives and watch video footage of the objective we were working on. They had regular webinars that covered a huge variety of topics. We could keep in regular contact with our consultant through this site. He would assign an objective, which we would work through with Nick. We would then send him video footage of that objective for him to comment on. However, at the end of the day, the cost factor plays a big part.

At this moment in time there are no RDI consultants in South Africa, although it is possible to get a long distance consultant. Now, just because we can’t afford a consultant doesn’t mean to say that RDI is totally inaccessible to us. Remember, it is all based on typical child development. I know that we don’t have access to the RDI parent and child objectives but there is reading material available to us. It is possible to buy the RDI DVD. I think I have watched that DVD at least six times, and I learn something new every time I see it. The internet is such a powerful tool and many of the RDI consultants have blogs. remediatingautism.blogspot.com is a great place to start.

Laurel Joss is a parent of a child with ASD and an RDI consultant. She has started the blog to help those parents who are unable to get a consultant and the information she gives is awesome. On a personal level, RDI has really grounded me. My lifestyle has slowed down…or perhaps I have learnt to manage my time!! I no longer rush from pillar to post. I enjoy the time I have with Nick and really treasure the progress he is making. Autism is no longer my life; it is a part of my life. Sure there are still stresses and strains of everyday living but I really try not to sweat the small stuff. Now, if I look back to my relationship with Nick before RDI, I can see that it was all one sided. Nick called and I ran! Nick was in control and I didn’t know how to change that. In fact he needed to feel in control because life was so confusing and he couldn’t cope.

In short;
• Nick was such an anxious little boy and very easily stressed
• He was so resistant to change. I recall driving a different route home from school and him being incredibly distressed. I wasn’t allowed in the room when he was being fed; if I stayed he refused to eat.
• Nick demanded a rigid routine, every thing had to remain the same, he was so static in his patterns
• He needed to be in control and unfortunately he was unable to self regulate
• Our family was in crisis mode and everything we did was revolved around Nick,
• We eventually stopped taking Nick out

There was also a missing link, the connection between us wasn’t there. Nick was a separate little being and it really was an ‘us and him’. Through being involved with RDI our roles have been reversed. We have been able to work on re-establishing our relationship and life is more natural…..well as natural as it can be when you have a child with autism! As mentioned before, RDI is an intervention that is based on taking steps to address the core deficits of autism. To explain further, the following is a basic overview of what we have been doing with Nick.

Building the guide/apprentice relationship
I was not capable of guiding Nick when he experienced uncertainty - as when encountering novelty or variation and he refused to let me guide him. The first thing I had to do as his mum was to build the type of trusting relationship that would enable me to interact with him and for him to want to learn from me.

Initially I just spent time in his space, sitting near where he was sitting, creating a bit of fun and getting him interested. I took advantage of opportunities, for example when he was sitting in the car seat I would take his hands and put them on either side of my face and gently hold them there until he showed resistance…...I was letting him know that I was there but at the same time I wasn’t putting pressure on him. If we were walking anywhere I would take hold of his hand and gently swing it….this may have been for only 10 seconds but the next time I would try for a little longer. I also played “I am coming to get you” and this built up some lovely interaction, excitement and anticipation.

My main goal for Nick was and is - is to introduce opportunities to encourage him to go a little bit beyond his level of competence so that the next time he feels more competent in his ability to engage and participate. The result has been that he has become competent as a participator in lots of different roles and different situations.

Referring
Nick couldn’t reference, read facial expressions or body language. Nick wasn’t able to look to me for information. His only way of communicating was pulling, crying and screaming. Yes, we used picture symbols and sign language to help him communicate but they didn’t contribute to our relationship.
We needed Nick to be able to understand that there was a lot more to communication than just being able to request his needs. We wanted him to become aware that by referencing our facial and body expressions he could get the information and emotional feedback that he needed to become an experienced sharing communicator.

It is difficult to recall our process to where we are today because it all comes so naturally to us now. A few examples that we used to help promote referencing included playing with beanbags - pulling/pushing this way and that. Hiding objects and really emphasizing eye gaze to enable him to find the object. I would be having a cushion fight with him and I would stop/pause the action and wait with an expectant look on my face........as soon as he looked to me I would pounce. This encouraged him to do it again and again. He began looking to me for more. I also over emphasized my facial expressions and I used sounds and changed the tone and pitch of my voice to encourage interaction.

Declarative Language v Imperative Language

Declarative, experience sharing language is any communication that is meant to share your ideas, feelings or experiences. Imperative language is any communication that requires a specific “right” answer, or that is making a demand.

Some examples of imperative language
What is your favourite colour?
What would you like for dinner?
What did you do at school?

Some examples of declarative language
I love that colour!
This morning, I went for a walk on the beach.
Hey, that’s cool!
Wow, I am so interested in what you are building.

Decrease verbal communication

Decreasing verbal communication is such an essential tool for developing joint attention. Nick has trouble processing verbal information; therefore, I am always aware of what I want to say, how I say it and how much I say.

This is where I must mention the 45 second rule. I give Nick time to process information, to think dynamically, problem solve and work out how to respond. I will make a comment either verbally or nonverbally and then wait (at least 45 seconds), if I keep repeating myself the poor boy is still trying to process the first bit of information and he is getting bombarded with more. If I keep my verbal communication short and to the point, Nick has an easier time understanding me and he is more likely to interact with me.

Increase nonverbal communication

In typical development, babies master the understanding of nonverbal communication prior to speaking. Nonverbal cues are a critical piece of typical communication. As told by Laurel Joss, “nonverbal cues help us to read between the lines during many of our daily interactions”. As a parent I understand that by us increasing the use of nonverbal communication has enabled Nick to understand and consider the emotional and social components which is so much more that just the words. Was Nick able to read nonverbal clues four years ago...absolutely not! As a family we have become quite competent at using gestures, facial expressions, body language and also the tone of our voices to communicate with Nick.

To date!

I would say that it has been the last two and a half years in which Nick has made the most progress. He still gets stressed and shows anxiety, however, he is able to self regulate and also look to us for reassurance. He is much more adaptable to changes in his routine, the places he goes to and the people in his environment.

Nick still loves his static routines and patterns but they don’t control him as in the past. He is able to transition with ease. Nick has learned to reference me and my actions (he will watch what I do to help him decide what to do). He can read my body language and facial expressions. Nick wants to be with us and communicate with us. We have fun!

He is becoming more of a dynamic thinker and his sense of humor is starting to emerge. He has started to initiate playful activities. We as a family give Nick the opportunities to think, adapt, solve problems and engage. These are all things that we have taught him through the RDI process.

Handy Hints

* SLOW DOWN……slow down the pace of interaction, the rate of speech, the amount of things you are attempted to accomplish.
* I try not to be repetitive in my use of language and I give Nick time to process information (at least 45 seconds).
* Show positive facial expressions...........this works so well for me if Nick is stressed...........he is learning from looking at my expression that “hey, it’s ok”, “its fine”.
* Remember the ratio of declarative language v imperative language. 70/30!
* Aim to build positive memories by spotlighting moments of competence.
* Regulate – challenge - re-regulate......Create regular patterns and make subtle changes – if the change is too much of a challenge, go back to the original regular pattern. This has really helped Nick learn that change is ok.
* Same but different........this is also a biggie that we use with Nick. This is another way of adding variations, changing patterns. An example I can give you is what I do with Nick’s snack box.......one day I will send his biscuit to school in a plastic bag, another day I will send it wrapped in paper or foil........so Nick is still getting the same biscuit but I have introduced a slight change with what his biscuit comes in. I bring this concept into all areas of the day......I will brush his teeth in the bathroom and perhaps the next night when he is in bed.
* Hesitate or pause the action to build up anticipation, a response.
* If needed, I use chanting to help Nick facilitate co-ordination with me and to ease transitioning.
* Another very important factor that I take into consideration is Nick’s sensory needs. He does get overloaded and at times he needs space. I provide him with sensory input when needed.
* I also use self talk so that Nick hears my thoughts and under stands how I organize things.....although this can be embarrassing when I am standing in the middle of the super market.

Should you require further information check out
www.rdicconnect.com
Di Maitland
dimaitland@tiscali.co.za
Ernie Els is launching the first ever “Ernie Els Computer Learning Centre” in South Africa. The Centre will provide FREE access to a well researched, highly effective web-based learning and development programme with one-on-one guidance from a trained professional for indigent families with children on the autism spectrum that cannot afford or access educational services. A new study concludes that less than 11% of children with autism in South Africa are currently receiving any beneficial intervention strategies.

Els for Autism USA and Els for Autism SA are partnering with Autism South Africa to create the proto-type Centre in the Johannesburg Headquarters of Autism South Africa. “We’re acutely aware that the majority of families in South Africa do not have enough money for food much less funds to access specialized education for their autistic child.” said Ernie Els. It was five years ago that Ernie and his wife Liezl received the diagnosis of autism for their son, Ben.

Since then the Els have worked tirelessly to change the conversation about what should be available to those on the autism spectrum. They are currently planning a catalytic philanthropic project, The Els Center of Excellence which will be built in Palm Beach County, Florida, USA. The Center of Excellence will include public charter school education for 300 students, medical and professional services, research, transition to adulthood and a major global digital learning program. “Our goal is to connect families all over the world with best practices for their children on the autism spectrum.” said Liezl Els.

The new Ernie Els Computer Learning Centre in South Africa is the first international linking with the digital learning program aspect of the Florida Center. The software treatment program is licensed from US based RETHINK AUTISM. It is designed for parents and professionals and offers a comprehensive curriculum, individualized assessment tools, staff and parent training modules, data tracking/progress reporting and ongoing professional support options.

The child’s strengths, weakness’ and developmental stages are entered into the RETHINK programme that personalizes an intervention strategy for the child. The attending educator will then ensure that the parent fully understands the intervention strategy he/she must follow with their child until their next session in the Els Learning Centre.

When the parent returns for the next session, the program will provide a questionnaire to establish the improvement in the child’s skills, whether the child can move on to the next stage of the required developmental path, or if the expected results have not been obtained in the interim period, an alternative approach is provided.

To ensure optimum benefits of this approach within the context of South Africa, initially two terminals will be installed at the Autism South Africa Headquarters in Braamfontein as a pilot program. An educator will work with two families per hour. Once it is confirmed that this programme has positive benefits for South African children with autism Ernie and Liezl will gradually open additional Els Computer Learning Centres around the country particularly in the peri-urban and rural sectors.

For additional information please contact:

Susan Hollo  
National Director  
Els for Autism USA  
susan.hollo@ernieels.com  
561-625-8267

Jill Stacey  
National Director  
Autism South Africa  
www.autismsouthafrica.org  
+27 (0) 11 484 9909

“One of my sensory problems was hearing sensitivity, where certain loud noises, such as a school bell, hurt my ears. It sounded like a dentist drill going through my ears”

Temple Grandin
Toys R Us has made a brand new friend

Toys R Us and Autism South Africa are working together to enhance educational outcomes for children with Autism and provide guidance for their parents.

www.toysrus.co.za

www.autismsouthafrica.org
My name is Vicki McCarthy and I am truly excited to be part of the BellaOnline community (www.bellaonline.com).

My Passion for special education and trying to make a difference started when my daughter was found to have special needs a few years ago. I assumed that everything she required educationally would be made available, however that’s not always the case and so our journey through the special education system begins...

My first career choice was as a nurse and through the years I enjoyed working both in the UK and USA. However when I became mum to my amazing daughter who is now 11 years old, it gave me a different perspective and I decided to become a Parent and Family coach, specialising in special needs.

Throughout the last few years I have researched special education and the issues surrounding it which has inspired me to want to help others. I’ve delivered presentations to various organisations and helped set up support groups for parents of children with special needs. My aim for the site is to provide you with up-to-date information, support, inspiration and to help feel empowered when you’re making educational choices for the child in your care.

My hopes for now and the future are to raise awareness of the challenges that people face when dealing with special education systems - from all points of view - including the children, parents, educators and professionals. Also to encourage collaborations between us all so that our children’s experience of special education allows them to grow and prosper, reach their full potential and just be their unique and beautiful selves.

Top 5 Tips for Parents attending Special Education Meetings

Having a child within the special education system can mean endless rounds of meetings and reviews and can add lots more pressure to an already stressful time for parents. Being your child’s advocate is no easy task, but is something that needs to be done to ensure their needs are fully met.

Those couple of days prior to a meeting can mean sleepless nights and lots of anxiety especially if you have had an experience of one that has not gone so well in the past. In fact, attending a meeting for your child can be downright scary!

So what can you do as a parent to ensure that you have a meeting which gives everyone the best possible outcome and as stress-free a time as possible? Here are 5 helpful tips to help you deal with those all important meetings:

• Be prepared
  Keep a note of all the things you want to talk about prior to the meeting. For example, your child’s strengths and weaknesses, things of importance that may be having an effect on them or any concerns or worries you have about them. When you have things written down it’s so much easier to keep track of everything you need to cover. That way if you feel anything is being missed you can refer back to your notes. There’s nothing more frustrating than leaving a meeting (which can sometimes take months to organise) only to discover there was something you forgot to ask. Also take a pen and paper with you and take notes. You’ll be glad you did after the meeting. It’s amazing how much of what was discussed can be forgotten.

• Speak to your child beforehand
  It’s a good idea to talk to your child before the meeting and ask them to identify anything which is troubling them or if there’s anything they want you to discuss at the meeting. This may not be possible for some children but if your child is able to contribute then allow them to. They may even want to attend for part of the meeting. Discuss with school staff if this is possible. Our children can make valuable contributions to meetings and allow everyone involved to see things from their perspective. Which, even as parents we sometimes don’t see.

• Take someone with you for support
  Sometimes as a parent it can feel very intimidating and lonely sitting in a room full of professional people. When you are in a stressful situation it can be so easy to let nerves take over. Take someone with you, whom you feel supported by. They may not even contribute to the meeting but just having them there by your side may help to ease some of your anxieties. They could also keep notes for you and give you gentle prompts if there’s a point you have forgotten to raise.
Try to keep your emotions in check
This is so difficult to do especially if your child is going through a rough time or if you have had a negative experience at meetings in the past. Where our children are concerned we can’t help but be emotionally involved. However if emotions become overwhelming they can actually get in the way of what we are trying to achieve. So try to remain calm and in control, no matter what is being said. If there is something that is being said that you don’t like or agree with, approach it in a calm and rational manner. People are more likely to listen and respect what you have to say. And whilst it’s difficult not to take things personally, try not to.

Remember that the other people in the room may be as nervous as you are.
This is something I had never given any thought to until I had a conversation with a teacher about it. She informed me that she always found meetings nerve-wracking and dreaded them. Somehow knowing this made me feel so much better about going into meetings and realising that the other attendees are only human (despite their title) and just the same as me. After your meeting take a while to reflect on both the negative and positive aspects of it. This will allow you to better prepare for the next one.

It can be very difficult for a child with special needs within the special education system to make friends and to maintain friendships. In fact generally it can be difficult for any child to make friends. We all remember how it was at school and the peer pressure that most of us experienced. However in today’s changing times that peer pressure is increasing and the feeling of having to conform, fit-in and be just the same as everyone else, is at an all time high.

So how do we ensure that children within the special education system who are different make new friends and maintain their existing friendships?

Well it begins with us, the adults. We all have a responsibility as parents and educators to ensure that special needs children are a part of a welcoming social group with their peers and not just on the fringes waiting to be accepted. We can tell children anything and they might listen. But children never truly learn from what we say but they always learn from what we do. Therefore it’s up to us to lead by example in all our interactions with other adults and children, regardless of who they are, where they come from or what difficulties they may have.

Teaching staff have a huge responsibility not only to teach the school curriculum but for helping to develop children’s social skills. However due to the emphasis on academic excellence very often the social aspect and the very basics of friendship often need to be neglected due to time constraints and results oriented school systems.

So while it can sometimes be difficult, in order for the students within a classroom to befriend a child with special needs, it is important that teaching staff and other staff members build a good relationship with that child and the other children within the classroom will often follow suit. Also children sometimes forget to be kind and loving to others (as we all do) and so we should give them small reminders often.

A great way to teach friendship skills to every child in the class is to adopt a “buddy system”, where each child who is struggling/has difficulties, is introduced to a friend or two who will be there for them at recess and lunchtimes. Not only can this help the child with special needs tremendously, it can also give the other children a real sense of purpose and give them the opportunity to develop compassion and acceptance in their truest sense.

Parents often struggle watching their child with special needs, hover on the periphery and not be truly involved in interactive play with other children. As a parent, a way to help your child develop friendships with their classmates is to take the time to get to know other parents. Invite their children around for play dates either at your home or even arrange to meet at the park.

However, it can be tiring being the one who makes all the arrangements and you may feel that you are always having to have children at your house rather than your child going to other people’s home’s. But for some people the concept of looking after someone else’s child with special needs can be a frightening experience. It’s not usually to do with discrimination but fear about not knowing what to do should any problems arise. It can often take time to develop them but with patience and persistence, lasting friendships can be formed with both the adults and children.

I’ve always been of the opinion that I would rather see my own child leave school with a solid group of friends rather than a bunch of qualifications and no friends. It’s only once you leave the school environment yourself and begin to make your way in the world that you realise the skill that takes you much further in life than any qualification, is your ability to interact with others in a loving and respectful way. Let’s teach this to all our children.
Parent Support Groups

Johannesburg
Bara & Natalspruit Hospital: Mary Moeketsi 082 580 7837
Genius Specialized Education:
Hugo Mendes 082 459 2311

Pretoria
Asperger Support Group: Lauren Schrempel 083 309 8654

Vanderbijlpark
Wings for Life: Margaret Dippenaar 083 254 0632

Witbank
Lisel Rhom 083 613 0225
Johannes Vermeulen 083 335 9804

Bloomfontein
Perto Vrooman 082 534 4516
Ilse Van Eck 073 660 7797

Durban
Di Maitland 083 443 8383
Action in Autism: Liza Aziz 083 777 4468
Allingham Primary School, Phoenix: Sheraine Reddy 013 563 5052

East London
Autism Sinethemba:
Antoinette Bruce-Alexander 043 748 3992

Cape Town
Autism Western Cape: Helen Hayes 021 5573573

Asperger's Support Groups

The Adult Aspie Social Group – ASCape meets regularly and if you are interested please contact Tanya Carter at tanyasc100@gmail.com or Tania Melnyczuc at news-editor@magazine.co.za for further details. You can also join the Group on Facebook @ ASCAPE. If you were interested in a youth group contact Natasha van Zyl (tasha@sibusisiwe.org.za ). If you were interested in a support group for those in relationships with people or children with Asperger's, contact ASCON, via Avril Meaker (021 7155255/083 666 2157/ameaker@telkomsa.net) or Jana Forrester (084 513 1333/janafor@telkomsa.net). This group is also on Facebook: Asperger's Connections – ASCON Support Group.

If you run a parent support and/or social group and you would like us to insert your details on this page in the next Aut;Talk, please send them to outreach@autismsouthafrica.org.

If you would like to be part of a parent support group in the Greater Johannesburg area please contact Trishana autismjhb@autismsouthafrica.org
Tel: +27 (0) 11 484 6448

Scarce resource hinders practical guide to key knowledge in dealing with Autism
compiled by Nhlanhla Kubeka

Autism is considered to affect 1 in 110 children and there is a dire need for parents and professionals to have easy access to information on the wide range of manifestations that are associated with this condition.

Getting information to parents and professionals in the rural areas and in the differing languages is paramount. Many adverse situations have been reported to Autism South Africa that have occurred as a result of people in the community not understanding why a child is reacting and behaving differently. Due to a severe lack of information and knowledge, it can be a long hard path for the parents before the correct diagnosis of autism is made. Often punishments are inflicted that cause great physical and emotional injuries damaging the child’s interaction with others, thus a downward spiral of rejection and exclusion of the child can start.

Professionals in the rural areas that do have understanding of autism need to proactively educate and support the parents. It can be extremely hard for the family to adapt to their autistic child’s needs, but with good basic knowledge there is a much greater chance that the child can be happy, stable, calm, successful and reach their full potential.

Families react differently to the diagnosis of autism and many spend many months and even years denying the presence of autism, hoping and praying their child “will come right”. De-stigmatisation of autism is essential as sadly some parents consider any disorder or disability to be an “embarrassment” or degrading to the family’s status in society. We turn to icons such as South African golf legend Ernie Els and US singer Toni Braxton who both have children with autism, to show people across the world, to have pride in their children with autism thus promoting inclusion and acceptance within society.

According to Jill Stacey, National Director of Autism South Africa, community leaders provide an essential route to destigmatise autism amongst more remote communities. Jill also stresses that communication channels may be limited across the vast expansion of the rural areas of Africa, but this does not mean that proactive and ongoing attempts must not be made to ensure distribution of information adapted for varying cultural and educational levels.
Celebrate Mothers – The unsung heroes of kids with special needs
written by Denise Kruger

“You will not receive a blue ribbon for all you have done and still do for your child. You will not have a medal pinned to your lapel, nor will you stand and bask in the applause of family and friends who so admire the sacrifices you have made and the monumental efforts you have put forth on behalf of your special needs child. You will, however, hear about the things you did wrong – who you slighted because you had to take your child to a doctor’s appointment, or how you should have pushed your child more and not coddled them so much.”

My journey with my son (Liam) started 4 years ago. He had just turned 2 and I was concerned that he was not speaking as a 2 year old should be. He would point to stuff when he wanted them and would do a whole lot of babbling. He would scream uncontrollably when I wanted to wash his hair, wipe his face or brush his teeth. He would also have a temper tantrum and really lose the plot, you could see in his eyes that he was not in the actual moment but totally out of it and the only way I could get him to come back to me was to physically hold my child down and it would take up to an hour at times even longer, this killed me inside as I felt I was losing my child and with many tears shed I could not help but to ask what is wrong with my beautiful boy?

I then decided to take him to an occupational therapist for an assessment and was informed that Liam had sensory integration dysfunction which is a neurological disorder causing difficulties with processing information from the five senses (vision, auditory, touch, olfaction and taste) the sense of movement (vestibular system). So it was decided that he have occupational therapy once a week. About six months after that I voiced my concerns on his developmental delays and was referred to an educational psychologist to have him assessed.

In April 2006 we spent an hour and a half with this psychologist and she said that even though he is a bit young to make a diagnosis there is a good chance he has Autism and was handed a booklet and sent on my way to come back in six months time to do another assessment. My immediate thought pattern was; what? No way! My child understands everything I say to him! This cannot be happening! Okay I need to drop Liam off at his day mother so until then I need to keep it together which I did and as soon as I got into my car I just broke down in tears, phoned my hubby we met for coffee and spoke about what this would possibly mean. The emotions I went through the days that followed was like a rollercoaster ride, that night I slept on the floor next to my son’s bed just to be close to him, the next morning when I gathered the strength to have a shower I just broke down uncontrollable sobs that came from somewhere so deep inside me that I did not recognize the sounds coming out, I will never forget my hubby came into the shower held me close to him and carried me out the shower and held me like a baby and just let me cry …………I felt like I was mourning the death of my normal child and of course the guilt that goes with it, what did I do wrong?

As a mother I decided that I need to pick up the pieces and life does carry on. I need to keep a level head, do research and wait until we go for the next assessment in six months time, which I must tell you was not easy it was hell!! Liam then started with speech therapy as well and that was also once a week. So we carried on with the two therapies and then it was time to go for the follow-up assessment. The Educational Therapist then advised that he did not have Autism (hooray!) as he makes very meaningful eye contact and is a very loving boy.

A recommendation was made he join a school which is for down syndrome children as she put in her report that Liam is “indicating borderline intellectual potential” As I walked out the spreek kamers I thought there is no way my child is going to that school and this would be my last visit to this professional’s office. My hubby looked at the report and was shocked to say the least so without me knowing he went and sought a second opinion and can I just stress here how important it is to seek that second opinion if your instinct is telling you to find the right professional to make the proper diagnosis!

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For more info please check out our homepage at www.planetkids.co.za, or email us at info@planetkids.co.za or call us on (021) 788 3070
I then took my son for a second opinion and he was then diagnosed with ADHD and signs of PDD. I must tell you that you do go through a period of grief, you grieve the loss of a normal child and then you reach the stage of acceptance. From that time of acceptance you do not look back, you go into “mother warrior” mode; you fight to get your child the help that is needed for him. I decided to stop working as I felt he needed me at home with him. I got him into a school for kids with developmental delays (Carel du Toit Centre) and he went for speech, physio and occupational therapies. I also had to attend a Parent Guidance session once a week at the school to enable me with knowledge and practical exercises to get my child to listen and progress. Liam was at that school for 2 years I then it was time that he went to Grade R so I had to find the right school for him a remedial school for kids with learning difficulties.

At this stage I also had to make the decision with regards to medication do I put him on medication or not as he was assessed again by a Educational Psychologist and it was found that he was making progress but not quick enough to get him school ready. So after three months of research and seeking medical professionals' advice and many many tears later I knew in my heart that I had to put him on medication and had to think of what will be best for Liam.

So then my search began to find the right school for my child. This was NOT an easy task as there are very few schools like these in the Western Cape and to go to a private school we could not afford financially. I eventually applied to two schools and then the waiting game began, it was unbearable I then put on my “warrior” hat again as their was one specific school that I wanted Liam to go to so after numerous phone calls to the education department, to the school where his application was sent, visits to the school and eventually speaking to the School Principal, I got a phone call about two weeks before 2008 December holidays to say he has been excepted – I was over the moon all my hard work had paid off!

Liam spent 2009 in Grade R at Jan Kriel School and was making progress but not to the level of School Ready for Grade 1 so we decided to keep him a year back and rather have him school ready. Liam went back to Grade R this year (2010) and by February his teacher voiced concerns that Liam was regressing and not at the level where he should be. I decided to have him assessed at SNAP (Special Needs Adaption Programme in Durbanville Cape Town). They confirmed with us that he has ADHD but also on the Autism Spectrum with PDD. So now our journey was taking us on a different path, just when you feel you have taken ten steps forward you get pulled 100 steps backwards again. I was told by SNAP that he needed to attend one on one tutoring 3 x a week for 2.5 hours a session. Financially I was not able to provide this for Liam so went about raising the funds, so my amazement a lot of ‘Angels’ stepped forward and made contributions and sponsored Liam for this programme. I call them ‘Angels’ as they really are – they have given my Liam a chance to achieve all he can achieve in this lifetime!

Liam is doing really great on this specific programme and is progressing well. He will be School Ready next year for Grade 1; he will still be attending the programme at SNAP. It is amazing to see how your child with special needs can blossom in the right environment and with the correct intervention. I am such a proud Mom!

There will be days that as mothers you want to get off this train journey and you feel you cannot do it anymore, and that is okay because in a couple of days you will get back on that train journey with more steam then ever and fight for your child. Everyday is different, if it is going to be a bad day then get through the day best you can for both of you. This is an incredible journey that your child is taking you on, you get to see the world through his eyes and you have been chosen to go through this journey with your child. Always strive for progress not perfection!

Thank you Liam for choosing me as your mom to go on this incredible journey of life through your eyes! I love you my angel!

Inclusive Solutions is the national suppliers of Assistive Technology and AAC equipment (Augmentative and Alternative Communication) for people with physical and/or communication disabilities.

Inclusive Solutions provides software, books, computer access devices, switches, adapted toys, eye control systems, communication devices and much more. This company also provide assessments, training and advice on all of our products. From basic resources to the very latest technology options, we are proud to offer the widest range of Assistive Technology products in Southern Africa.

Unit 89 Block 8B, Northgate Office Park, Aureole Avenue, Northriding
Tel: +27 (0)87 940 2532 or +27 (0)10 590 2532
Fax: +27 (0)86 614 4106
Mobile: +27 (0) 71 648 2526
Email: ed@inclusivesolutions.co.za
Website: www.inclusivesolutions.co.za
Autism is a broad band of varying degrees and areas of ability, challenging behaviour and severe learning difficulties. Those who attend a special needs school (preferably autism-specific) from a young age, are fortunate to be accustomed to a structured routine suited to their specific individual needs and to be taught life skills in order to be as independent and capable as possible when older.

But where do they go from here…….

Once the child reaches the age of 18, they have to leave school and the implications from this day onwards are enormous. Parents then face the most difficult challenge of all: Where do I send my young adult who is probably still going through puberty and struggling to understand and cope with hormonal and physical changes, mood swings, emotions, not quite fitting into and being accepted within “normal” society, and this is over and above their frustrations with the condition of autism, and needing structure and intellectual stimulation? The person with autism most often requires constant supervision and guidance all day, every day – all this is quite exhausting for a family, parents or single parent to cope with! When the person with autism is at home, a clear, strictly controlled, routine with suitable occupation needs to be put in place – this can prove to be quite a task, especially when no or very little help is available to the family. Most often there seems to be very little, if any, support, from extended family and sometimes this is due to ignorance or fear of the difficulties and condition of autism.

Although there is an increase in public awareness of autism and related difficulties and the need for suitable facilities, this is an area that will always require ongoing attention and care. The future of persons with autism, in their adult years, their financial needs, their daily occupation and routine, social interaction, and stress on their families, is of great concern. In today’s economy it is more often than not, essential for both parents to work to satisfy the needs of a family. In some cases, there is only a single parent who has no option, but to provide for the family. The person with autism is then left with a nanny or char or other family member, who probably has no experience or proper understanding of persons with autism, never mind the energy and time available solely for the demands of the person with autism. Training in this area is becoming more available, but can also be costly. This kind of desperate situation can be damaging and stressful to the person with autism and can result in displays of frustration in moods, tantrums and aggression. We can add here that this is, of course, not the only reason for aggression in the person with autism – but can increase any existing behaviour problems.

The Academy for Adults with Autism is a body of concerned parents who have formed a non-profit organization in order to raise funds for and to cater for the needs of these young adults. Our focus is “A Better Life for Adults with Autism” and our ultimate aim is to provide a residential care facility specifically for adults with autism in Cape Town. Although a small but dynamic group, we have met our short term goal of establishing a work center for adults with autism where adults spend time, weekdays only at the moment, eight until four thirty, Monday to Friday, performing activities and jobs that suit their ability. They are given opportunities to pursue new occupations with close guidance and support from staff and are encouraged to also partake in art and music therapy. They are taken on a daily outing e.g. a brisk walk to a nearby park and are encouraged to be friendly and polite to others at all times. We believe in the importance of exercise and diet which go a long way to providing a better life for adults with autism. The Academy for Adults with Autism has much to achieve in its ultimate goal of a residential care of a high standard in order to support the person with autism and relieve their families of the burden of coping with the daily needs that autism demands.

Assistance with fund raising and any other areas of need are most welcome. Please contact us via our website. Visit our website [www.adultswithautism.org.za](http://www.adultswithautism.org.za)

“A BETTER LIFE FOR ADULTS WITH AUTISM”

Autism Western Cape is under new management.
Welcome to Helen Hayes, who is the new Chief Executive Officer.

Tel: 021 557 3573
Fax: 086 671 9120
Mobile: 079 551 1463
ceo@autismwesterncape.org.za
www.autismwesterncape.org.za
A new Guinness World Record for Endurance Boxing was set on Saturday, 24 July at exactly 23:00, when Monta Vista resident, 20 year old Tom Varley punched his black boxing bag for the last time after a ground breaking 38 hours.

Tom started the challenge on Friday, 23 July at 09:00 at Canal Walk Shopping Centre, Century City and joined forces with Autism South Africa to raise awareness and funds for Autism. The majority of autistic children in South Africa do not have access to beneficial education and the funds will also benefit local Durbanville charity, SNAP, together with Hurdy Gurdy house, a house for adults living with autism.

SNAP Academy is currently trying to raise funds to build and equip a Grade 2 class for 8 special needs learners with Autism or Severe Developmental Delays. What made this event extra special, is that Tom himself, although never formally diagnosed, suffered from the symptoms of Aspergers since he was a little boy and found sports a great way to deal with and overcome his social handicaps.

I have had the privilege to be involved in the event, not only from a Public Relations point of view, but also as a mother of a child living with the effects of this neurological disease every day. For me, the past two days was nothing short of an epic emotional journey.

For the first few hours I merely watched Tom as he punched the bag in front of him with determination, never looking beyond the task that he has set out to do. I noticed his isolation and was immediately taken back to the lonely road we started on, since the diagnosis also became a reality in our family. His determination matched ours in our pursuit to find answers and the many roads it has lead us on.

I suddenly realised that this was not just a boxing event - Tom's fight became a symbol of hope - a beacon for every child, parent and family that ever had to deal with the devastating effects of this journey.

Every punch took me back to the obstacles I had to overcome during the past four years. First, the helplessness of seeing my child disappear into a world of his own, then the constant struggle to make a connection, the attempts to make eye contact, the struggle to find meaning in his words, shows of affection and random acknowledgement in his eyes.

About an hour after he started, he was joined by the Grade 1 learners of the SNAP Academy who came to show their support.

Tears started streaming down my face when I saw these special children enter the boxing arena. They were each handed a pair of boxing gloves and supported to punch the bag themselves. Their fight is not one that lasted 38 hours, but every minute of every day. Tom's face lit up and he picked up the pace when the children joined him. He cheered them on, taking the time to connect to each of them whilst keeping his steady pace.

I stayed with him until 3 am the Saturday morning and then went home for a break. Saturday morning I phoned in to find out how he is holding up, praying that he will be able to finish this. Somehow it seemed extremely important to me that he should not fail. But I underestimated the determination of this young man with the big heart.

Victory was sweet when Tom, not even looking tired, broke the World Record at 23:00 on his 20th birthday. Later on he posted a message on Facebook saying that the record meant so much more to him than than hitting a bag for two days straight and that it was his way of showing everyone that he would never give up on life again because the rewards are beautiful.

Closer to home, our 5 year old autistic son, also had the opportunity to punch the bag in support on Friday afternoon. Tom had the following words for him: "Jandré you can overcome any obstacle or hardship that faces you. All you need to do is have faith and realise the potential greatness within you. You might be a little bit young to understand this now, but one day it will become perfectly clear to you. God bless you kiddo"

The World Record has been broken, the stage dismantled and the supporters have gone home, but for most of us, the fight is far from over. However, the stakes had just been raised.
The team developed a strategy during the course of 2010 that seems to be an effective model. The principles that were followed are:

* Although Vera School manages the team, they are not based at Vera. They work on identified sites where preliminary work has been done. The preliminary arrangements include assessing the readiness and infrastructure of a site interested in assimilating Autism into service.
* The minimum staff compliment allocated by the service is a qualified teacher and teacher assistant.
* It is beneficial to all if the assigned staff and the principal attend the Vera course before implementation take effect.
* Use existing specialized schools who are enterested and strategically positioned to develop Autism classrooms or units. This is cost effective as there is already an infrastructure allowing the team to start with autism specific interventions almost from day one.
* It should be a whole school approach where the principal is involved as the leader who drives and establishes the project. The other staff should be involved to foster maximum understanding and buy in. It has been the experience thus far that other staff soon learn that Autism Specific Interventions can also greatly benefit other learners with special needs and this is motivating to embrace Autism in the school.
* The team works collaboratively with staff members of the resident school who are assigned to work with the learners with Autism directly. It is an experiential model where observation, assessment, programme design and guided implementation happen on site for new learners with Autism that are admitted to the school or for already enrolled learners with Autism.
* The time frame for implementation is at least one term per ‘satellite’ school.
* After initiation, regular follow up is done to assure maintenance and to offer continued support and development.
* The management of the team is done by regular visits to their sites. Included in this procedure will be meetings with the principal and other development strategies.
* Long term goals are defined at the outset and pivots around the idea of a quality service that will eventually apply for registration with Autism South Africa (ASA). The team works at sites to effect service and therefor will remain for at least a term, rather than moving around continuously raising awareness and offering information. The emphasis remains on capacity building and empowering staff to become good Autism practitioners.
* Boland School in Paarl, class rooms at Chere Botha School and Beacon School in Mitchell’s Plain have been established thus far.

Vera School
20 Anglesey Road, Rondebosch East, 7700
Private Bag X4, Clareinch, 7740
Tel: +27 (0) 21 696 2844
Fax: +27 (0) 21 696 4877
Email: info@vera.co.za
www.vera.co.za

Vera School is regarded as the provincial resource centre for Autism by the Western Cape Education Department. An outreach team, paid by the department and managed by the school, has been allocated on an ad hoc basis for 2010 and 2011. The probability that they will be appointed permanently, is high. The team consists of a Psychologist, an Occupational Therapist, a Speech Therapist and an Educationalist. The brief of the team is to build the capacity of other professional and non-professional staff to deliver an Autism specific curriculum to learners on the spectrum who cannot be accommodated in the existing specialised schools for Autism because of long waiting lists and other logistics.

Our knowledge about Autism Spectrum Disorders (ASD) and effective treatment methods has significantly increased over the last 35 years. For the broad spectrum of impairments there is now a spectrum of acknowledged intervention methods. This manual gives an overview of best practice interventions including applied behavior analysis, precision teaching, experience-based and visual approaches. These methods are integrated into the curriculum component of this manual, called STEP (Structured Therapy and Experience-Based Programs). Guidelines are presented for parents and professionals to match the child’s skill profile, learning style and interest to the best possible intervention method. Numerous case studies, examples, sketches and pictures make this book very reader-friendly. Reproducible forms are provided for skills assessment, data collection and teaching in the following areas:

- Attention, Eye Contact, and Joint Attention
- Matching and Sorting
- Imitation
- Language Comprehension
- Active Communication and First Utterances
- Expanded Communication
- Play and Social Behavior
- Self-Help Skills and Independence
I am happy to announce that Action in Autism won the empowerment award from The Institute of People’s Management at their 16th Annual Women’s Convention hosted at the ICC, Durban on Thursday 29 July 2010. We received a beautiful trophy and an amount of R10 000 in recognition of the work we are doing to support a community of people with autism. Our social bring and braai hosted on 24 July 2010 to support families of people with autism was a wonderful and rare opportunity for families to socialise and connect in an embracing environment. Our mass awareness campaign on 24 April 2010 to commemorate World Autism Day was a resounding success. For the first time a community of people connected by Autism marched through the City Hall precinct, campaigning for autism. Holding aloft posters, distributing 1000 pamphlets in isiZulu and English, family members and community supporters did their share to spread the word on autism. It was an empowering experience with members of the public stopping to ask questions on autism. Inside the hall, parents told their personal stories of diagnosis, early intervention, adult services, community and hope. Psychiatrist Dr. S. Salduker and Dr. Margie Lilienfeld provided their expert views on autism. Deputy Director of Inclusive Education, Thabisile Zondi expressed the Department of Education’s commitment to children with autism. We were entertained by the beautiful sounds of the Ningizimu Special School’s Steel band with the sounds of our children with autism at play in the background. It was a happy day of community spirit, engagement and knowledge sharing.

Our Board of Management of the early learning intervention centre: Chairperson: Paediatric Neurologist: Dr. Lawrence Mubaiwa, Chairperson of Action in Autism: Liza Aziz, Retired Special Needs Principal: Sam Moodley, Educator: Kirsten Miller, Speech-Language Pathologist and UKZN lecturer: Saira Karrim, and Parents: Mthokozisi Mchunu and Ramdhani Diaram; continue to meet on a monthly basis. Our resource centre has thus far served 120 families, some searching for information, guidance and counseling, most requiring educational intervention for their little ones with autism. The second class at the Early Learning Intervention Centre opened its doors on 10 May 2010. This class caters for 6 learners. In total we have 12 learners with autism receiving daily intervention. We have also accepted a learner who is both blind and autistic – a learner that was turned away from all other early learning centres. The centre offers an autism specific, school readiness curriculum that establishes and builds on the basic skills needed for learning and learning readiness.

The resource centre continues to run from 8h00 - 15h00. We offer information booklets (in 6 official languages), articles, and books, DVDs a resource list and a list of all the schools in the province as well as a comprehensive list of all the health care professionals that offer services for our children with autism. Our bi-monthly development workshops have been extremely successful. We hosted 16 workshops thus far. The expertise has included Di Maitland, parent and Principal of Kids First, Dr. Margie Lilienfeld an Alternative Augmentative Communication specialist; Debbie Omar, a Speech-language Pathologist, Mayesveri Pillay, a sensory integration Occupational Therapist. We also hosted a Makaton workshop, presented by a doyen in the autism world, Margaret Golding who has some 30 years of experience working in the field of autism. We continue to screen documentaries on autism. The network of peoples, schools and professionals involved in autism has increased tremendously through our development workshops. Action in Autism together with Autism South Africa co hosted a National Conference on Autism on the 9+10 February 2010 at the Graduate School of Business at UKZN. This was a resounding success with 280 delegates attending.
A sleuth of 16 national speakers on autism presented. Action in Autism was also instrumental in getting the Provincial Department of Education to commit to a proposal to develop further educational units catering for children with autism. Historically, Action in Autism has been pivotal in lobbying the Department of Education (KZN) to open 13 autistic units in 13 special needs schools across the province of KwaZulu Natal. Action in Autism’s Educators’ Forum meets on a monthly basis and is a chance for educator’s to share best practice and discuss challenges in the classroom. This is an important initiative to support the educator in the classroom. It is also a wonderful platform for open dialogue between schools in the public and private sector. Our Parent’s Support Group meets on a monthly basis - providing much needed support and knowledge to our parents. Thus far we’ve had a fantastic line up speakers: Psychiatrist, Dr. MS Salduker addressed parents on the uses of medication for autism, tax expert Arshad Ameer workshopped parents on how to full out a tax return for families with disability, educational psychologist Viona Odendaal addressed parents on “How do I discipline my child with Autism.” As part of our inclusive philosophy, Chris Sparks an adult with Asperger’s Syndrome also addressed parents on “Living with Aspergers.” Our last support group meeting looked at the theme Education: Setting Realistic Goals. 3 principals of Special Needs Schools made presentations. We have also initiated a monthly sibling support group meeting that runs concurrently with the Parents Support Group.

Our therapy section is thriving. Highly experienced Speech-Language Therapist Debbie Omar continues weekly therapy sessions with our little ones enrolled at the centre. We are happy with our partnership with the UKZN School of Speech-Language and Occupational Therapy who continue to send final year students for practical experience to the centre. Seasoned Occupational Therapist, Aneesa Moosa has joined our team on a weekly basis. We have embarked on a new way of therapeutic intervention – a much more integrated approach – which involves the speech-language therapist and the occupational therapist working together with the educator and the classroom facilitators within the classroom. Each learner enrolled in the school receives a comprehensive Tran's disciplinary approach to intervention with the team meeting on a regular basis to discuss the progress of each learner and input into each Individual Educational Programme established. We meet with parents on a one on one basis every term for input and progress on the Individual Programmes. Educational Psychologist, Viona Odendaal has assessed each learner enrolled at the school on the Griffiths diagnosis tool – this has been utilized as a baseline score to establish each learner’s individual education programme. In addition to this, Dr. L. Mubaiwa has kindly donated the CARS test to the early learning intervention centre for a more accurate assessment of our learners.

We are happy to say that we are in the final stages of developing our monthly neurology clinic. We are at the present moment accessing equipment to establish this unit. Paediatric Neurologist, Dr. Lawrence Mubaiwa from Inkosi Albert Luthuli Central Hospital heads this division. This will provide a monthly diagnostic clinic for all children suspected to be on the spectrum. The centre is situated in an under resourced area and hence the service will be provided for those most in need.

Plans for our protected workshop for young adults and teenagers with Autism Spectrum Disorders are underway – the projected timeline is June 2011. Most school leaving young adults sit at home because there are no provisions made for them. The envisaged centre will provide a protected workspace. We are still accessing funding to make this a reality.

Yours in Autism Awareness and Action!
Liza Aziz
Chairperson: Action in Autism

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**An internet brower for Autistic Children**

Get to know the tool, but also the story behind this brower especially designed for autistic children to work quietly and efficiently in front of the computer on the internet. John LeSieur, an IT programmer who lives in Las Vegas(USA), thought that surfing the net could help in the rehabilitation of this 6-year-old autistic grandson, Zachary.

However, he quickly got discouraged when he realised that the great amount of colours, advertising banners and bright contents of the net confused little Zac even more.

Therefore, he decided to create his own browser, especially designed for children with autism. He named the brower ZAC(zone for autistic children), after his grandson, and it is available, in English and absolutely free at [http://www.zacbrower.com](http://www.zacbrower.com), for whoever needs it.

*The browser was originally designed for 6-year-old Zachary*
Autism Sinethemba: We are Growing!
written by Antoinette Bruce-Alexander

Autism Sinethemba is a registered Non-Profit Organisation that was established to care for the needs of Pre-School aged children in East London with an Autism Spectrum Disorder. As yet, we are not funded by Government and throughout we are entirely reliant on Fund raising initiatives and Donations.

We opened the first classroom of our Early Intervention Centre on the 27th May 2008 – the only Autism Specific Pre-School in the East London Area - at the St. Pius Catholic Church, 1 Kitchener Street, Cambridge. We started with 6 children of different ethnic backgrounds, abilities and of both genders. The children’s ages range between 3 yrs and 6 yrs. Very recently we applied to a Trust Fund in Cape Town – The D.G. Murray Trust - for financial assistance and we were thrilled to receive funding for some of the expenses of our second classroom!! We are now able to educate another 6 children and will take children up to the ages of 8 years. Our teaching hours will also increase to 5 hours a day for the older children. We now employ 4 Staff members; two qualified Pre-school Teachers with Foundation Phase training and experience and two Xhosa speaking classroom assistants to help with the language barrier in teaching children with Autism. Our first Teacher underwent the intensive VERA School training at the Quest School for Autistic Learners in Port Elizabeth to assist them with Screening and Assessment and the teaching of the little children with Autism in East London. Our new teacher and assistants will be trained as soon as the Vera School training is offered at the Quest School early next year again. We are well equipped with the basic items for a Pre-School for one classroom at the moment and we are doing fundraising like crazy to set up the second classroom. Our main goal is to prepare the children to cope and fit into a mainstream school and to be able to benefit from the Department of Education's Inclusive Education Policy and Outcomes Based Education System.

Wish List:
Because of the long waiting list of children that need urgent placement in a Pre-School with Autism Specific Teaching methods and materials, we were hard pressed to open a second classroom for another 6 learners at our Early Intervention center. St Pius Catholic Church informed us that they have another classroom available for us to use. (We have had discussions with the new priest in charge and we have recently signed a contract for a two year period for two of their classrooms.)

We need:
1 x Large Work table for group work, 2 x Filing Cabinets, 1 x Vacuum Cleaner, 2 x 3m x 3m carpets, Outdoor Toys for water play and sand play, Clean sand for the sand boxes PLUS toys, Outdoor Playground Equipment, Rocking Toys (eg. Rocking Horses); Interactive toys; Educational Toys, games and Computer Games, 1 x Classroom Computer, Coloured printer, Various stationery items, 4 x Bookcases on wheels, 12 x Blackboards on Easels, Set of swings, 2 x Security Gates and Monitored Security System

We estimated that the above cost would be in excess of R50,000.00. Should you wish to help, please contact Antoinette Bruce-Alexander (043 748 1849/072 678 2452)

Bonang Botse Autism Centre: Request for Donations
written by Dignity Mothapo

Bonang Botse Autism Centre started in January 2009. We have 15 children on the Autism Spectrum and their ages range from one to sixteen years old. I built the structure from my own funds (R30 000) and it consists of a playroom, one bedroom, one kitchen and two pit toilets. It is a boarding facility which offers Life Skills in various ways via Personal Health Care, Arts and Culture, Vocational Skills and Sports, e.g. gymnastics for people with disabilities. I pay someone (R500 a month), from my own pocket, to help me with the children, without her help I would not be able to manage. There is a vegetable garden in the centre where we have planted mealies, sweet potatoes and pumpkins which we use to feed the children.

My request is for the Following:
Wheelchairs, blankets, mattresses, carpets, toys, first aid kits, a laptop, a photocopy machine, vegetable and flower seeds and two gates (one for cars the other a pedestrian gate).
Most of the parents are unemployed, they spend the disability grant of their ASD children on educating their able children, groceries and services (lights and water). As a result they are unable to pay school fees and boarding which costs R350 per month per child.

I hope and wish that some of my requests will be realised and will be most grateful for anything we may receive.

Should you wish to donate anything, please contact Dignity Mothapo(082 957 6358).