

Interface Kwa Zulu Natal

291 Underwood Rd, Sarnia,
Pinetown
P.O. Box 1995, Westville, 3630
Tel/fax: 031 708 4237
Cell: 076 819 6750
E-mail: lfackzn@saol.com



**Centre for Augmentative and
Alternative Communication
University of Pretoria**

Tel: (012) 420 2001
Fax: (086) 719 2666
www.caac.up.ac.za



University of Pretoria

ISSN 1018-2071

Contents

- ◆ CAAC News.....2
- ◆ Interface Branch News6
- ◆ School news.....6
- ◆ Let's get practical.....8
- ◆ Tech Talk.....8
- ◆ User Forum9
- ◆ Feature articles.....10
- ◆ For your diary.....12



**Centre for Augmentative
and Alternative
Communication**

CREATING NEW OPPORTUNITIES

National Newsletter

Survival strategies for the year-end: Stop, drop and roll!

Well, well, 2011 is almost drawing to a close! For some of you, this may mean things are winding down.... For others (and I guess I could include most of us here) the year seems to gather momentum at this time, and one needs to master the juggling act to keep all the balls in the air! Looking back, it has been a particularly busy and productive year for the AAC community, with many projects, events, trainings, workshops and awareness activities. You will get a glimpse of these in the pages following.

It would come as no small surprise thus, if most of us, by the beginning of December, feel genuinely tired. So... time to stop, drop and roll. If you are not sure what these words relate to, it seems you did not pay attention during fire drill instructions. Stop ,drop and roll is a method to extinguish fire on one's clothes. It is simple and effective and can be taught even to children. It is also a life strategy – particularly to prevent burn-out. And the end of the year is, for many of us, an ideal time to implement it.

Stop: After a busy year, allow yourself a chance to cease from the frantic activity for a bit. Take a breath. Get some distance from the doing. Of course there is much work and little time, and some responsibilities don't just go away. Yet a time to recharge, refresh, reflect, refocus and gain perspective is a key ingredient to health, inner peace and ultimately more effective doing.

Drop: Let go of the unnecessary baggage. Drop the worries about oh so many things that are beyond our

control. Many things work out better than you think. Drop your dwellings on failure – nothing more debilitating than mulling ad infinitum over things gone wrong. Success is not the absence of failure, but having the courage to get up and go on. Drop the offenses – keeping you captive while the offender goes free. As a dear friend of mine would put it – build a bridge and get over it.

Roll: Move it! Move it! Make the effort to become a bit physical – whether that means a 10km jog, dancing to your favourite song or walking around the block. Try to get out – onto the beach, to a nature reserve, your garden or your local park. Breathe some fresh air, get a work-out, clear your mind and get a fresh perspective.

Wishing you a fire-free December! Thank you for your hard work and support throughout the year, keeping the AAC field moving forward. See you back bright-eyed and bushy-tailed in 2012!

**Kerstin Tönsing
Editor: Centre for AAC**



Interface promotes communication for people with little or no functional speech by supplementing existing communication with gestures, communication boards and assistive technology (thus, augmentative and alternative communication)

Centre for AAC news

Graduation

The University of Pretoria spring graduation ceremony was held on 5 September 2011. Magdel de Klerk obtained her PhD (AAC). Her topic was: Young South African children's recognition of emotions as depicted by Picture Communication Symbols.



Two students, Aurellia Gonasillan and Ange Behringer, graduated with their Master's degree in AAC. Aurellia's study looked at the application of a language development survey within the South African context, while Ange looked at the application of a Talking Mats procedure to determine preferred topics of conversation in adults with LNFS following stroke. A further 123 students graduated with an ACE (inclusion of learners with severe disabilities).



Congratulations to all of the graduates. We are very proud of you!

New Eye Gaze system for Centre for AAC

The staff at the Centre for AAC is very excited about the Tobii C12 and CEye eye gaze AAC system that the Centre recently acquired. On the 18th of October Lisa Ellis from Inclusive Solutions presented training to us on the use of this system to enable us to assess clients that may benefit from its use.



Often, clients with severe communication impairments also have physical disabilities, which make it difficult for them to access technology such as a computer in the regular way.

The state of the art Tobii C12 and CEye uses a camera, infrared lights and software to enable the user to control their computer, communication software, environmental controls (such as television remotes/lights), camera and mobile phone by using only eye movements to control one integrated system.

The availability of this amazing technology has the potential to unlock doors for many people with severe physical challenges, including those with athetoid cerebral palsy, Locked-in Syndrome, high spinal lesions, Motor Neuron Disease and Multiple Sclerosis. The Centre for AAC can be contacted for consultations at 012 420 2001.

Karin van Niekerk
Centre for AAC

Assistive Technology for the Classroom - Northern Cape Project

From July to October this year the Centre for AAC was involved in an assistive technology project mandated by the Northern Cape Department of Education. As part of the implementation of Inclusive Education, the Northern Cape is focusing on addressing communication barriers experienced by learners through providing appropriate Augmentative and Alternative Communication (AAC) strategies and systems in the classroom.

Three schools from the Kimberly area were selected to take part in the project, these being Retlameleng, Jannie Brink and Kimberley training centre. Fifteen learners from these three special schools were selected and assessed by staff from the Centre for AAC. We identified their communication problem areas and arranged for appropriate devices and low-tech strategies aimed at enhancing their communication skills and learning. Educators were trained how to use the following software programmes and AAC devices: Go Talk 9, Go Talk 20, The Grid 2, and Boardmaker™. They were instructed on how to use the latter programme to make daily schedules and communication boards. They were also given ideas on how to implement these in the classroom. Follow-up visits to the classrooms allowed for in-situ training and collaborative problem solving to ensure strategies were helpful in the classroom situation.

In completion of the project, the AAC trainers, the participating schools and the DoE officials gathered at the District office to share their experiences about the project. The DoE officials encouraged the three schools to work collaboratively and share their resources with schools that need this assistance. The teachers reported that they learned that the consistent use of devices can increase learners' participation in learning and reduce dependence, helplessness and isolation.

Conny Simelane
Centre for AAC



A learner participating in an assessment

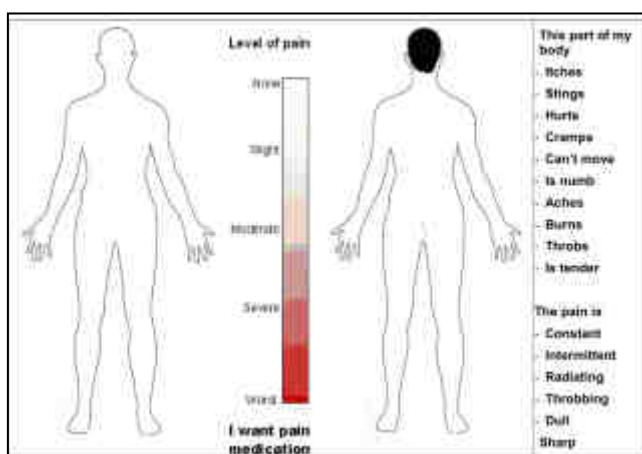
Some of the teachers, DoE officials and Centre staff that participated in the project



An Introduction to AAC in Primary Health Care Settings

A one day training was conducted at Germiston Hospital by the Centre for AAC. The main aim was to introduce and demonstrate the value of the use of AAC strategies to improve communication with people who have little or no functional speech in the Primary Health Care context. The training involved an introduction, to AAC, high and low technology AAC strategies, and how to develop an AAC Assessment Tool Kit for the primary health care context. This comprised 10 basic items and AAC strategies that could potentially be used on a variety of AAC candidates. In addition Pain Charts were introduced to assist those with severe communication difficulties and even those who experience language barriers to communicate about the location and severity of pain they experience. A total of 55 professionals from Primary Health Care facilities were trained including 12 occupational therapists, 2 aids, 11 speech language therapists, 10 physiotherapists, 7 podiatrists 3 optometrists, 7 professional nurses and the deputy director and health coordinator of PHC.

Dr Shakila Dada
Centre for AAC



Extract from a Pain Chart

Speech Therapy Conference

Kerstin Tonsing and myself (Michal Harty) recently returned from the 2011 ENT/SASLHA/SAAA conference which was held in Port Elizabeth. We had the opportunity to address the audience on 3 separate occasions. In the speech and language strand a variety of topics were covered ranging from feeding difficulties in paediatric clients, through to where does speech-language therapy fit into genetic medicine. We had the privilege of listening to Dr Sally Peterson-Falzone, a Clinical Professor Emerita at the University of California in San Francisco. Dr Peterson-Falzone has a special interest in craniofacial anomalies. Kerstin and I spoke in a session that focussed on inclusive education. In our presentation we spoke about the importance of promoting AAC in an inclusive classroom. We highlighted the fact that many AAC strategies are useful not only during individual therapy sessions, but can also be used with all the learners within the classroom. AAC strategies such as a focus on core vocabulary and aided modelling can

improve the language and literacy development of many children in the classroom who face challenges, even although they may not be candidates for AAC. A personal highlight for me was listening to a fantastic presentation about inclusion in action by Mrs. Buffy Allanson, head of pre-primary at Theodor Herzl, a school implementing inclusion in PE. For more information about the CAAC presentations at SASLHA please visit our website: www.caac.up.ac.za.

Dr Michal Harty
Centre for AAC

AAC Awareness: Walk for a Voice

It was a lovely spring morning with jacaranda trees in bloom when the Centre for Augmentative and Alternative Communication hosted Walk for a Voice at the University of Pretoria. The staff at the Centre for AAC, along with learners and staff from the Pretoria School, Pathways Pretoria, New Hope School, Unica School for Learners with Autism and representatives from the Association for Autism as well as the Down Syndrome Association and other interested parties participated in the event. We walked the 2.2 kilometre "yellow route" on the UP campus, which opened in October and is the first route at UP delegated as wheelchair friendly.

The purpose of Walk for a Voice was to bring attention to augmentative and alternative communication, particularly since October is AAC awareness month. With over 200 learners and staff holding signs and walking together across campus, we drew considerable attention and many UP students inquired and learned about AAC and how AAC can give people without natural speech "voices". The learners took their job of distributing pamphlets and stickers very seriously and made sure nobody 'escaped' being made aware of AAC. All the walkers had lots of fun – and those for whom the route grew a bit too long bumped a ride on one of the golf carts of the campus security or on Cival Mills' electric wheelchair.

Thank you to all the dedicated walkers who took the time and put in the effort to put AAC on the map. We would also like to thank Bestmed for sponsoring bags for all participants and Johan Pretorius for the sponsorship of snacks.

Dr Dana Donohue
Centre for AAC



A colourful procession on the UP campus



Kosie Schoeman supporting the Walk (Ride?) for a Voice initiative

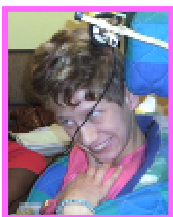


Students were given stickers and pamphlets to inform them about AAC.

FOFA 2011

After an absence of 1 year the Fofa project was again successfully presented 19 – 23 September 2011. We were lucky to have 3 new participants this year. Nkosinathi Nthuli and his mother Gladys are from Soweto. Nduduzo Nzimande and his cousin Thandeka came all the way from KZN and met their first challenge on Shaka Zulu airport when they heard their flight was cancelled! We were so happy that they eventually made their way successfully to the Jacaranda city! Carla van Niewenhuyse is a friend of Tsholofelo Phiri, who already attended Fofa and she inspired Carla to join this year. I do not think Carla was disappointed as her family was so proud of her achievements after just one week in the programme. She never thought she would work so hard during the week. Apart from Tsholo (who is already an old hand in the programme), France Mgenge, Constance Nthuli and Felix Visagie also revisited the Fofa programme.

Lebogang Sehako was invited to be a lecturer during this Fofa week. Lebo was a Fofa participant for the past 6 years and he is actively pursuing his dreams to be an advocate for people with disabilities. As he shared his journey with the participants, everybody was inspired and could see that dreams can be reached, despite your disability. It is just a matter of visualizing your dreams, putting them on paper and starting to make plans step-by-step. The staff of the CAAC was again instrumental in realizing the first steps of the participants' dreams. Constance developed a CV which she can present to possible employers in the food industry. France has written his first article to the CAAC newsletter and has the contact details of community newspapers in his area for which he is planning to write articles addressing disability and universal design issues in his own community, for example the fact that the local KCF is inaccessible for wheelchairs and prams. Felix wants to use his prior knowledge as an electrician and apply it to improve the durability of wheelchair batteries. And in his words, he is "... going to make a lot of money...".



Tsholo and Carla inspired the management of Westrand Centre for People with Disabilities so much that they asked them to start with a newsletter for the institution. They are therefore already realizing their dream, which is to use their communication devices to tell people about their life journeys and their new-found and previously hidden abilities. In this way they are becoming advocates for people with disability.

Nduduzo has big plans to study further, but he realized that he has to re-do certain Grade 12 subjects. This was an important lesson for all of us. We need to assist our learners with disabilities to perform to their maximum potential. Then learners do not have to go back and re-do subjects in order to be able to study further. In the meantime, he got connected to the internet and email so that he could stay in contact with people to support him in his dreams. Last but not least, the youngster in the programme, Nathi, wants to become involved in radio media. He wrote a letter to a radio station explaining his dreams and requesting to shadow people in the business to discern if this is what he will be able to do.

While working on making their dreams a reality, they realized that without being competent in using their communication devices,



their dreams will stay only dreams. About 60% of the time spent in the programme is focused on becoming competent communicators with their devices. Being on the campus of the University of Pretoria gave a perfect opportunity to test communication abilities with unfamiliar people such as sales personnel in the canteen. Both parties gained from this exercise!

During the customary Friday presentation ceremony, we distributed a "Dream List" of all the participants to the audience and Felix then started the initiative of "paying it forward". After long deliberations, he donated a brand new manual wheelchair to France. Filicia Baret from Maranatha Bana donated an electrical wheelchair to Fofa! We are still deciding who the recipient of this wonderful gift will be – thank you for your amazing generosity, Filicia! Waxbill Capital donated a data stick to every Fofa participant, which will come in very handy. Thank you for your continued support and generous gift. The "Dream List" is on our website if anyone would like to contribute and pay it forward.

FOFA is inspirational, not only for the participants, but also for those of us that have been granted an able body for now. We truly hope that the participants and all of us too will continue to dare to dream and have the courage and perseverance to actively pursue these dreams, and spread our wings to fly.

Prof Kitty Uys
Centre for AAC

For more information about the Fofa project, please contact the Centre for AAC.

FOFA Feedback



Thank you for this year at Fofa. It empowered us. I would like to say thank you to the two helpers, Mamma Connie and Karin who helped me. I learned so much and I enjoyed it. The party on Tuesday night was wonderful! I enjoyed commu-

nicating with new people and to meet Sean who is a special friend. After Fofa Carla van Niewenhuyse (who attended for the first time) and I did our speeches at the centre where we stay, and we made our voices heard. We also now do a newsletter for our centre.

Tsholofelo Phiri
Fofa participant

FOFA: The Journey to Pretoria

Going to Pretoria to join the Fofa project is a opportunity to learn more on what you would like to do, or what you can do. Fofa helps us to open our eyes and get to realize that to feel ashamed of yourself won't take you nowhere. When I go there I get this feeling that I will give all my best. Often where I connect with new people I get the impression that many of them think that a person with a disability won't be able to do anything. But its not like that, its more like a person with a disability can do more than you think.

When we are there in Pretoria we talk about our dream. What do we wish to do? How will we do it? This year was a different story for me. There were quite a few new faces and it felt more serious. One thing I like about Fofa is that you are free to say what you feel inside and ask questions if needed. They get people to come and advise us on what we must do. One of the people spoke about budgets, which was important for me. It's important to save money because when you start counting on how much you spend every month you just get shocked.

When I first started dreaming it was to be a DJ. I love music because music makes you feel excited. It makes you forget all your worries and pains. I chose music because I like to entertain people. I like to see people enjoying themselves. For me I'm not only



DJ but also a producer. So I can also produce my own music which I think is quite cool. When you listen to a track you get to think that to produce music is easy. I always thought like that but when it was time for me to produce my own tracks I thought "WOW what a job".

But if you love something and you feel it then you just have to do it. My second dream is to write articles or to write stories. I like writing articles on something which worries people, articles which get people talking. I really thought about it – music is only for entertaining people. But to write articles for newspapers it can end up to be a job. I also thought of writing a book. But to write a book is not a joke. You have to do research on what your book is going to talk about. But I feel that to write articles is more doable for me. I want to write articles about drugs and abuse of children as these are issues what worry people a lot. What do we do to stop drugs? Another thing is abuse. Why are there people abusing children these days. Every time when you listen to radio or watch TV you always hear that a guy raping a young girl or killing a child.

That is my dream, so if you read newspapers please look for my name, France Mgenge, because that would be my article there!

France Mgenge
Fofa participant



More FOFA feedback



It was my privilege to work closely with Felix during the Fofa-week as his mentor. We worked very hard on his future plans and dreams. During his presentation on the last day of Fofa, Felix shared some of his dreams with the audience. At the end of all the presentations, Felix surprised France, one of the Fofa-participants with a brand new wheelchair. This Dr Cival Mills, also an AAC user and long-standing friend who was part of the audience remembered this kind gesture of Felix. When Cival read on the AACSA email list of a second hand Lightwriter with voice output for sale, he decided to surprise Felix with an early Christmas gift. This small ceremony took place during the Unica Christmas Market where Cival was also exhibiting his books, DVD's and artwork.

Ensa Johnson
Centre for AAC

Here is Felix's feedback on the Fofa-week as well his thank you to Cival:

End of August/ beginning of September) it was Fofa time. At Fofa (were we all use A.A.C equipment to talk, give speeches or to make jokes with) we learn to stand up for ourselves and to make speeches (if you can't speak it doesn't mean you don't have anything to say).

With all that been said I want to thank a very old friend of mine Dr Cival Mills whom I met a few years ago at Physio classes. We sat in the same canoe. It had a v8 motor that pushed us around (we were both too lazy to row it so we chose the model with a motor on it). Cival sells T-shirts, hats, and has even written two books. Cival donated a Lightwriter to me – one that speaks whatever you have to say.



Cival, THANK YOU, you changed my life for ever!

Felix Visagie
Fofa participant

Interface Branch News

Interface KZN

The intervention team made up of Dr Margi Lilienfeld, Kirsty Nourse and Jocelyn Mngomezulu will be undertaking visits to various schools in the last term of this year, continuing into 2012. This is following on from requests from a number of schools for support and guidance, assessments, training and advice on suitable resources. The schools that we will be visiting include St Raphael's School, Khalipha School, Inanda Special School and Day Dawn Special School.

We are very excited to announce the start of our Communication Circle. This initiative aims to provide an opportunity for young AAC users to get together socially and develop friendships, to be mentored by effective AAC users, and to have opportunities to develop communication competence. The Communication Circle currently runs one Monday afternoon a month from the Interface KZN AAC Resource Centre, and is being facilitated by Kirsty Nourse. Dan Ngcobo has so far participated as a Mentor. Young AAC users attending the Circle may be accompanied by a family member, caregiver or friend, but most importantly, someone who is an existing communication partner. The last Communication Circle for the year will be on Monday the 14th November, and the group will be having a Christmas party. Should anyone wish to join as a participant or become involved as a mentor, please contact Gail at our centre.

Interface KZN has also become involved at Robert Storm House at the Natal Settlers Home, in Umbilo. The unit houses children with multiple disabilities, most of whom have little or no functional speech, and whose ages range from 3 to 23 years. Interface has become involved in Storm House with the aims of facilitating the use of AAC and integrating AAC into the daily routine, supporting and training staff, and doing individual assessments and intervention as needed. More about this in the article following. It is a long-term project, with a lot of challenging work ahead. We are planning to put a formal proposal together before the end of 2011, so that we can motivate for funding for the various aspects of this project.

A short while back Dan Ncgobo's laptop needed to be replaced. An appeal was put to the Interface KZN committee to assist Dan to acquire a new laptop. Money was graciously donated by outside individuals and Interface KZN was able to purchase a new laptop, for which Dan was very grateful!

We are ending our year on a very sad note, as we have to say goodbye to our super-efficient Office Manager, Gail Ngcobo. Unfortunately, for Interface KZN, Gail's husband is being transferred to Gauteng and they will be relocating at the end of this year. It has been wonderful having Gail as a part of our team and we wish her all the best for the move and the New Year.



Leandra Hinds
Chairperson: Interface KZN

Robert Storm House Project

Interface KZN has, since June 2011, been nourishing a partnership with a local care centre for children and young adults with cerebral palsy and significant physical impairments. The unit cares for 25 individuals, all of whom have little or no functional speech. All except one or two are seated in buggies and wheelchairs and another two or three are seldom taken out of bed due to frailty and severe contractures.

Currently the partnership consists of weekly visits by myself, Jocelyn Mngomezulu during which I screen the individuals who are housed at the unit. I also talk to the unit staff to build awareness of AAC and highlight some of the cognitive abilities of the children they care for. I am working regularly with a couple of the children who are learning to discriminate between and use individual PCS and will hopefully soon progress to full no-tech PCS communication booklet. School placement will be next up on the agenda for these young ones. I also spend time with the management of the establishment, who recently consented to a partnership to start a day care programme with a range of activities, all of course coupled with implementation of AAC. Interface KZN has a huge role to play in the training of the individuals who would run this programme as well as continuing advocacy and awareness for the residents' cognitive stimulation and development.

Jocelyn Mngomezulu
Interface KZN

School news Pathways Pretoria

The learners and staff at Pathways Pretoria celebrated the arrival of spring in style this year. The Squirrel Class put on an amazing puppet show for the rest of the school. The little squirrels dazzled us with a fun and interactive farmyard extravaganza, complete with music and puppets on sticks operated by the learners and facilitators from behind a curtained stage. What better way to celebrate the arrival of spring than with a carnival of animals?



Pathway's annual spring day was marked by a visit to the Moreleta Kloof Nature Reserve. As keen supporters of Casual Day, we all

wore stickers and adhered to this year's 'takkies' and 'rock and roll' theme. There were some rather unusual and rock and roll outfits on the scene! The learners and staff enjoyed a picnic outdoors and a mini hike on the wheelchair-friendly trail. After the long winter, this was a welcome treat for all!

Spring heralds new beginnings and the team at Pathways are eagerly taking on fresh, new initiatives and projects. The 'Kids for Kids' Project is underway and we look forward to the challenge. This project, which is part of our school-to-work transition, involves Pathway's learners directly. The learners pack the recycled material that is used to compile educational toolboxes (each containing 40 different activities) for children in under-resourced areas. We are also starting to use our new Pod Books on Wheels in our classrooms. These books are a hands-on and interactive tool which makes Picture Communication Symbols (PCS) an integral part of all classroom activities.

Elizabeth Steward, Pathways Pretoria

Pathways Roodepoort

In July, Team Pathways Roodepoort 2011 had a spectacular adventure with 19 hikers trekking through the breathtaking Fish River Canyon in Namibia in order to raise awareness and much needed funds for the Centre. Mother of Crystal Raine and founder of Pathways Roodepoort, Julie Botha, said it was a very tough journey for her, and likened her struggle through the Canyon to the immense difficulties she faces as a mother of a child with special needs. She said, "The obstacles faced along the journey are immense and yet somehow, with a bit of help from my friends, I made it. As in life with Crystal Raine, I have found that when the going gets tough and there seems to be little hope of a good outcome, something wonderful inevitably happens to show me that with faith and a little help from my friends, I will prevail and find a way forward. When I was at my lowest points in the Canyon (and there were many), I thought of Fay, our Principal, with her team of dedicated staff, and the faces of each child in her care would appear in my mind and I was able to take the next step and continue. My daughter was always with me in my mind and I really learned a lot about myself on this arduous adventure."

Sharon Pauer, a precious friend of Pathways Roodepoort and wife of Pathways Roodepoort's Chairman, went out of her way to ensure that this trip was an enormous fundraising success for the Centre. She planned the trip down to the last detail and the entire group had an unforgettable experience. Sharon's target was for the team to raise R40,000 and she was delighted when the support and momentum for the expedition grew and surpassed all her expectations. Over R60,000 was raised! Team Pathways Roodepoort walked 87km through the second largest desert canyon in the world for children who navigate through their own life of incredible difficulties every day. The team sank down into the canyon with packs of between 15 and 23kg's on their backs. They

struggled through 24 icy river crossings, scrambled over enormous boulder fields, up steep canyon walls and slept under a diamond studded sky on beaches next to the mighty Fish River, too exhausted to care about the blisters on their feet, the pain in their muscles and their physical tiredness. Pathways Roodepoort's Chairman, Wilhelm, reminded the team each morning as to why the journey was so important and gave courage to each Pathways pilgrim, as they walked for special needs children. Oom Eugene, led the team through this arduous terrain expertly, safely and successfully and each member emerged at Ai Ais as heroes, having conquered their own physical battle and having finished for the children they carried with them in their hearts every step of the way.



To every single hiker, Pathways Roodepoort says a heartfelt "thank you". To everyone who sponsored team members on this trip, a BIG THANK YOU !! Without you believing in the possible success of the team, we would not have raised this much needed funding. To Sharon Pauer, who organised the entire expedition, with careful planning for over a year, but could not join us herself due to being pregnant with a long-awaited baby, Pathways Roodepoort says "thank you for everything you always do for the Centre! You are the most unselfish, loving and giving person we know and we wish you every success with the birth of your baby boy!". How wonderful it is to have friends like these to help carry us through a sometimes extremely difficult journey.

Jewel Botha
Founder: Pathways Roodepoort

Pathways Kloof

We had a wonderful Sports Day on 22nd October 2011, followed by Bring & Braai for the families. All in all it was a fun day. We also sold crafts made by the children bringing in a much needed R2500.



Ebrahim Essack used Clicker to tell his story.

On Saturday we had sports day. It was so much fun. Mom, dad, Nazeera, Nanni and Joyce all come to watch. I rode the bike and I ran in the races. I also threw and caught the ball.

Jenny Head
Pathways Kloof

Bryant English used PCS symbols to tell his story for Sports Day.

I threw the ball with my hand and I was riding a bike at school on sports day.

Let's get practical!

“Spell it out”: Partner-assisted spelling

Partner-assisted spelling is an AAC strategy that is used worldwide in many languages. It is an inexpensive, (relatively) easy-to-use system for people living with communication challenges, who are literate, but have significant mobility challenges. It requires only one consistent movement/sound from the AAC user, to indicate a choice to the communication partner/facilitator. As the communication partner recites the letters of the alphabet, one by one, the AAC user selects the letters to form words, phrases and sentences. Whereas pre-selected words and phrases are often used to enhance the rate of communication, it may limit the AAC user's utterances, as he/she can only communicate using the words/phrases that somebody else selected for him/her. Spelling out words and phrases gives people living with communication challenges access to *generative* language, i.e. the ability to write whatever they would like to write, albeit with the help of a facilitator.

A variety of spelling systems are utilised worldwide, including using the alphabet in its standard form. This requires virtually no training for the AAC user or his facilitator/communication partner, but is very slow, as the facilitator might have to recite most of the alphabet just to get one letter. This causes communication breakdown, frustration and fatigue.

To make the spelling system faster and more effective, the alphabet is divided into different groups and the AAC user is essentially doing group-item scanning on an auditory and/or visual level.

The alphabet can be grouped, according to letter sequence in the alphabet, e.g.

1) a b c d e f g	2) h l j k l m n
3) o p q r s t	4) u v w x y z

This would be the same in all languages using 'standard' letters (based on the Latin alphabet). Some specific characters may need to be added, e.g. š for Sepedi, or ë for Afrikaans.

The alphabet can also be grouped, according to frequency of letter use in a specific language. Thus, letters that are used more often for written language, are placed in one of the first groups that are recited, to allow for faster and easier access. Groups of letters can be indicated either with different colours or with different numbers.

The partner reads through the list of colours/numbers, one per second (or slower if required) and waits for a response from the AAC user as to which group he/she chooses. Subsequently, the facilitator reads through the letters in the selected group, one letter per second (or slower if required) and waits for a response from the user as to which letter he/she selects. It may help the facilitator to write down the letter, for example on a whiteboard, in

order for both the AAC user and the partners/facilitator to keep track of the spelling process. Once a word has been spelled, the facilitator should confirm that he/she understood correctly, before continuing with the next word. A method whereby the AAC user can indicate the end of a word may also be helpful, such as closing his/her eyes.

Below, please find the partner-assisted spelling charts for Afrikaans, English, Tswana and Zulu. These are based on analysis of written text regarding the frequency of the occurrence of letters in the text. For more information, please contact aac4africa@yahoo.com.

English		Afrikaans
a e i o u y (pink)		a e i o u y (pienk)
s t r p n (blue)		m s r k t (blou)
m b c h l d (orange)		d l h g b (oranje)
f g k w (green)		n v p w (groen)
j v q x z (yellow)		j f z c x q (geel)

Tswana		Zulu
a e i o u y (pink)		a e i o u y (pink)
t s d h l m (blue)		m h g n s k (blue)
n b p r k (orange)		b l d r t (orange)
g w c f (green)		p w f j (green)
j v q x z (yellow)		v c q x z (yellow)

Elmarie van der Merwe
 Founder: AAC4Africa
aac4africa@yahoo.com

Tech Talk

The AAC-RERC

WHITE PAPER ON MOBILE TECHNOLOGIES AND COMMUNICATION APPS

In the past two years there has literally been an explosion of mobile technologies (iPads/iPods/tablets) and AAC applications (apps) being used for people with complex communication needs (CCN). These mobile technologies fill a much needed gap in the often expensive AAC device market as a more affordable alternative to dedicated AAC hardware-based solutions. However, there is a growing concern amongst many in the AAC field that these purchases are often made without careful consideration as to whether they are appropriate for the specific users abilities and needs.

/....

The AAC-RERC (cont.)

The Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC) White paper on Mobile Devices and Communication Apps which can be found at <http://aac-rerc.psu.edu/index.php/pages/show/id/46> comes therefore at a very appropriate and exciting time in the history of AAC and aims to guide the field when these technologies are being considered.

The White Paper presents a measured view of how these apps are impacting on the available range of AAC options and services while at the same time presenting some valuable and thought-provoking comments which are worth reading if you are in anyway involved or interested in AAC as a parent, user, interventionist or researcher. In compiling the white paper more than 25 AAC “thought leaders”, representing multiple stakeholder groups, were interviewed between January and March, 2011. Some of the concerns noted are the lack of technical support, quality control, durability and customization (especially when users are unable to use direct selection) of mobile technologies. These all have important implications for the very serious issue of device abandonment when these tools fail to meet expectations. (Read Michelle Aronson’s account in this issue for a valuable personal insight). Mobile AAC technologies therefore have to be held to the same standards of control to which dedicated AAC technologies are subject to. Thus it is the White Paper’s assertion that a cautious and holistic approach to mobile technologies needs to be taken and consumers need to be knowledgeable about the options which exist so that informed decisions can be made. The authors also note that a positive outcome has been a general increase in AAC awareness and encourage the AAC community to engage in continued research and development in this exciting time in the field. The AAC community should therefore become involved in developing and improving AAC applications in order to help match mobile technologies to the real world experiences of AAC users.

Locally the use of mobile AAC technologies also evoked an interesting debate on the AACSA list serve aacsa@kendy.up.ac.za recently with parents, researchers and interventionists, even catching the ISAAC president Erna Alant’s interest as she provided some valuable contributions. Margi Lilienfeld shared a memory of something Erna always used to say which is “you don’t give a child a piano and expect them to be a pianist”. Finally we need to be reminded again that ultimately “augmentative and alternative communication has always been about the communication, not about the devices and technology.” (p.10) and that we need to be using a range of technologies, low tech as well as high tech, to advance a person’s communication abilities. Mobile technologies therefore represent an exciting addition to the communication repertoire of current and potential AAC users but they are not a universal remedy or panacea for all communication challenges.

Alecia Samuels
Centre for AAC



User forum

AAC is not a “one size fits all” solution – a personal account

My daughter, Jamie, requires an AAC system as her speech is simply inadequate to be understood by those who are unfamiliar with her. Throughout the years, we have tried various options. Jamie does use key word signing but many of her signs are idiosyncratic and are thus not understood by her communication partners outside of our immediate family. Jamie, however, did not like a communication book and devices such as the GoTalk were too limiting in terms of the vocabulary. Furthermore, although she is computer literate, a computer (which is readily available) loaded with “The Grid 2” software is also not practical as it is too heavy for Jamie to carry around and takes too long to load every time it starts up.

As such, I was extremely excited when I read about Apple launching Proloquo2go for the iPod touch. The benefits of this device are that it is easy and relatively cheap to buy the iPod and download the software. Moreover, it is straightforward to program the device and music, videos and games and accessories can be downloaded as well. The “cool” factor should not be overlooked for a teenager and the iPod is light and can be carried around as an accessory.

However, and much as I regret to say this, the iPod is still inadequate to meet Jamie’s needs for a number of reasons. Firstly, she struggles to scroll slowly. Now, when you have a category like “actions” with pages and pages of options, the scrolling becomes an issue which results in great frustration. Secondly, constructing a sentence on the iPod touch is a relatively demanding motor exercise. The user must select the category for the first word and find the option (often by scrolling). It is then necessary to go back to the ‘home’ page before the category containing the next word can be selected and so on. This process is rather unwieldy and can be difficult to carry out fast enough to facilitate effective communication. A third problem we encountered with the iPod was the small size and the close proximity of the letters on the keyboard. I personally find it difficult to type on this keyboard.

Weighing up the negatives against the positives, it was decided that the iPod touch should be used as a backup system for Jamie. The optimum device that was recommended to meet most of her communication needs is the Dynavox Express which had to be imported from USA. Whereas the Dynavox is portable, sturdy and meets most of Jamie’s requirements, the cost is prohibitive. However, I am happy to say that with much perseverance and patience, we have received a significant proportion of the cost back from medical aid.

In summary, the point that I am stressing here is that the selection of an AAC system must be person-specific in order to be functional. The process is one of trial and error which is difficult in the face of the exorbitant costs of high-tech AAC devices!

Michelle Aronson
AAC consultant

Feature articles

Multiply Silenced!

The sad reality in South Africa is that we accept and acknowledge that we have a huge problem with the abuse of both woman and children, but we largely ignore the shameful reality that both children and adults with severe disabilities are at high risk for abuse, including sexual abuse. And the very individuals who are most at risk are those who do are not able to speak! They are not doubly silenced but multiply silenced as:



1) Their inability to speak intensifies the 2 highest risk factors for abuse, namely dependence and vulnerability. Because of their dependence, caregivers (at home or in institutions) of either the same or opposite gender are involved in intimate care. Many children and adults who do not have functional speech are also dependent on caregivers or peers interpreting for them, making them dependent for communication. In addition, right from early childhood children with severe disabilities are taught to be compliant to adults working with them and this physical dependence on therapy, medical procedures, daily care etc. reduces the child's natural opportunities to set and understand personal boundaries. In fact, many children with severe disabilities undergo painful or uncomfortable procedures that may be fairly intrusive and the child may even be coerced or bribed to be compliant in these legitimate situations. The child may then have difficulty in differentiating between legitimate demands (based on medical or therapeutic necessities) and abusive demands of adults "caring" for them.

2) If and when they do try and communicate the abuse they are ignored, disbelieved or misunderstood. The experiences of practitioners working with children with disabilities (medical, educational social workers, psychologists and therapists) and NGO's such as Childline, Save the Children and Interface KZN reflect that abuse against children with disabilities is extremely high and often met with disbelief. This is despite the fact that children with disabilities display the same non-verbal signals of abuse including loss of appetite, crying, bed-wetting, sleep disturbances, changed behaviours ranging from apathy to rage and aggression, that are displayed by children without disabilities. Often these changes in children with disabilities are attributed to the disability instead of the abuse.

3) When they do actually manage to communicate the abuse and are believed, they still do not have access to the criminal justice system. In May this year I was contacted with respect to four incidents of abuse relating to six children who use AAC who had suffered physical and/or sexual abuse. All of these incidents were being handled 'in-house' i.e. by the school or agency whereas if these incidents of abuse had occurred with children who were typically developing they would have immediately been referred to the police and thus the criminal justice system. In fact there is little published information on the incidence of abuse (sexual or physical) on either adults or children with disabilities in South Africa.

4) There is a lack of protocols with respect to the admissibility of evidence by plaintiffs or witnesses using various forms of AAC within the justice system. Recently in preparing an expert witness report for a government department I could find no evidence relating to this issue in current literature and was fortunate to get the information I required from Diane Bryen of Temple University in the States as she has recently, in collaboration with Christopher Wickman, prepared a paper on "Ending the Silence of People with Little or No Functional Speech: Testifying in Court". The only cases that I could find documentation of related to Deaf individuals who were using SASL.

5) Myths abound in South Africa regarding the sexuality of people with disabilities. People with disabilities are frequently presumed not to have sexual feelings and desires like everyone else. Often they are also assumed to be "virgins". There is of course the opposite "myth" that children with cognitive disabilities are "over sexed" or are "precocious" about sex. However, I would like to suggest that the most significant myth is that abuse of children with disabilities does not happen. There is also the additional myth that when abuse does occur to children with disabilities, it is somehow considered to be less harmful to the child!! Add to that the myth that children with severe disabilities do not need sex education!

We as parents and professionals in the AAC field in South Africa have avoided this distasteful subject for far too long. We need to start to address this problem with a multi-prong approach including the following:

* We need programmes to stop abuse before it starts and to empower children and adults who require AAC to know their rights and to fight back. For starters every person deserves to have a voice! Children who require AAC also need training in healthy sexuality and assertiveness. Children need to have the vocabulary and means to tell a trusted adult if they are being abused.

* We need to raise awareness of this issue and as confirmed by Diane Bryen the starting point is "collecting the stories".

* We need to advocate and to educate parents, caregivers, educators and therapists regarding the potential risks and signs of abuse including the indirect ways of regressive behaviours, or angry "acting out" behaviour. We know that being cared for outside the home is another major risk factor for abuse and so need to have checks in place at school hostels and residential institutions. As is the case of children without disabilities who experience sexual abuse, the perpetrators of abuse are most often people who are known to the child. In a 2008 USA survey of sexual abuse of children with disabilities, 44% of the perpetrators were service providers related to the disability, for example residential care staff, transport or attendant personnel, whereas 32% was attributed to family members or acquaintances. Until we collect the stories we have no data to suggest that it would be otherwise in South Africa.

* We need to facilitate intersectoral collaboration – there are already wonderful initiatives in place with regards to abuse of children and we need to liaise with these programmes such as the Teddy Bear clinics, the child protection units of the SAPS and with the justice system and provide those working in the prevention and remediation of abuse with the training to facilitate the same processes with children and adults who have disabilities and require AAC.

We do not have to re-invent the wheel as there are resources and models developed that we can adapt or use. Examples include the

extensive Speak-Up project from Canada, Diane Bryen's Speaking-Up and Speaking Out: Reducing the risk of becoming a Victim of Crime and Victim in Times of Emergency, resource books e.g. Combating Violence and Abuse of People with Disabilities: A Call to Action by Nancy M. Fitzsimons; Sexuality: Your Sons and Daughters with Intellectual Disabilities by Karin M. Schwier and David Hingsburger and Safe Beginnings: Protecting Our Children From Sexual Abuse by Orieda Horn Anderson and Shirley Pacey which is aimed at pre-school children, to mention just a few. Rebecca Johns from the Western Cape also runs an excellent education program on lifeskills, sexuality and HIV/Aids for learners with intellectual disability.

The CAAC are to be complimented on making a start on this subject in August 2009 with the 2-day Speaking Up and Speaking Out workshop by Diane Bryen that resulted in the development of both picture symbol and alphabet/word boards in several languages that can be downloaded from CAAC website under the menu title of "Abuse Boards" (URL: <http://tinyurl.com/PCSabuseboard>). As Diane noted during the co-presentation with Prof Juan Bornman and Priscilla Kershaw of the CAAC at the 2nd Regional African AAC conference last month "Persons who use AAC know that silence isn't golden".

Let's start to break that silence.....

Dr Margi Lilienfeld
margi@lilienfeld.co.ca
 0824668254.

Indiana Institute on Disability

Magic still exists. Sometimes it is expected and obvious: we all experienced it when Prince William married Catherine and we could see a modern day fairy tale come to life. Sometimes it comes as a totally unexpected surprise that leaves you in awe. That is how I felt after visiting Indiana University's Centre for Excellence in Developmental Disabilities: Indiana Institute on Disability and Community (IIDC).

Situated in Bloomington, a leafy university town, home to Hoosiers, this institute was started in 1970 when a former disability institution was changed and restructured to become this modern facility. Their mission is clear: "To work with communities to welcome, value and support the meaningful participation for people of all ages and abilities through research, education and services". Can you see the similarities between the Centre for AAC and the IIDC? In order to realize this mission, they are driven by the following ideals:

- ◆ Life span focus, from birth through older adulthood
- ◆ Emphasis on community
- ◆ Unique partnership and
- ◆ Strengthening connections between university and community.

This huge task is carried out in seven different Centres, each with a unique focus, that fall under the Institute's umbrella:

Centre for Disability Information and Referral: This is the primary information dissemination source for people with disabilities, their families and professionals through their library and website – be sure to take a look!

Indiana Resource Centre for Autism: With the world-wide increase in the prevalence of Autism Spectrum Disorder (ASD), this centre is active in conducting outreach training such as workshops, university courses, opportunities to do practical work, engaging in consultations, conducting research, and developing and disseminating information to professionals and parents through newsletters, brochures, videos and the web.

Centre on Education and Lifelong Learning (CELL): Focuses on working with schools and communities to include, educate and support all learners.

Centre on Community Living and Careers: Focuses on improving transition to adult services through person-directed approaches, career development, community living and membership. One project, SEARCH Indiana, provides transition age youth with internship experiences in order to prepare them for employment in the open labour market.

Centre on Aging and Community: Provides leadership, enabling older persons to lead self-determined lives within their communities e.g. through self-advocacy training, a leadership series, consulting and training programs, website development, etc. One of their exciting projects, "Building Leadership Series" focussed on three 2-day workshops over a 3-month period for a total of 5 years. Eighteen participants with intellectual/developmental disability participated in the small and larger group activities, role plays and brainstorming and problem solving activities – very much like our Fofa-project. Three main topics were included: Choice, rights and responsibilities; self-advocacy and person centred planning. Each of the workshop topics had a lovely companion workbook that followed along with the presentation and allowed the participants to make short notes and complete some key ideas. Be sure to look this up on the website for more information!

Centre for Planning and Policy: This centre has a state-of-the-art "collaborative work lab". This technology lab is set up to assist with group activities in order to generate more innovative ideas, engage more effectively in group processes, to participate in a more democratic way and to develop more creative products. Recently this centre conducted a survey focussing on the implementation of the Americans with Disability Act (ADA) across five different states in the US, with some very interesting results.

Early Childhood Centre: Providing a gateway of information, services and resources for early childhood professionals (e.g., providing news for professionals, professional organizations and continuing educational resources) and families of young children (e.g., on child care and early education, health and safety, parenting and family support).

So don't miss this opportunity to look at the great work that the IIDC is doing: iidc@indiana.edu



I am sure that each one will find the specific centre that is related to the work that you are involved with, and that you will be provided with relevant information. Let the magic start for you too!

Prof. Juan Bornman
Centre for AAC

For your diary...

Pixon training

A picture-based communication system can be wonderful – and a real frustration due to the limited vocabulary! The Pixon Language Project from the Prentke Romich Company focuses on the use of a small set of high-frequency words (core words) represented on manual communication boards to encourage not only communication, but also language development in persons with little or no functional speech.



Maureen Casey, an AAC specialist and Pixon trainer will present a Pixon workshop on the 14th of April 2012 at the CAAC to introduce the use of the system. A Pixon kit consisting of CD's and other material will be included for each attendant.

Don't miss this amazing opportunity!



Notes: 2012 dates

JANUARY 2012

- 20 January:** Extended closing date for applications to Honours & Masters degrees offered through the Centre for AAC.
- 31 January:** 15th Biennial Conference of ISAAC: Early bird registration closes

APRIL 2012

- 14 April:** Pixon training

JULY—AUGUST 2012

- 28 July—4 August:** 15th Biennial Conference of ISAAC Pittsburgh, PA, USA
- 15—17 August:** 11th World Down Syndrome Congress 2012

SEPTEMBER 2012

- 18-22 September:** Fofa 2012
- 22 September:** Fofa Programme Open Day at CAAC

APPLICATIONS FOR POST GRADUATE DEGREE STUDIES

Should you be interested in studying for the BA Hons (AAC), MA (AAC) or M (ECI) degrees at the Centre for AAC, University of Pretoria, please contact us for further details at saak@up.ac.za, or tel 012 420 2001.

WALK FOR A VOICE



Having an AAC chat