

Centre for Augmentative and Alternative Communication CREATING NEW OPPORTUNITIES

# **Interface National Newsletter**



# Centre for Augmentative and Alternative Communication

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Interface promotes
communication for
people with complex
communication needs
by supplementing
existing communication
with gestures,
communication boards
and assistive
technology (thus,
augmentative &
alternative
communication)

#### Individual Highlights

Interface South Africa	Page 2
Regional News	Page 2-4
School News	Page 4-5
For your diary	Page 5
Aided Language	Page 6
CAAC news	Page 7-8
Users' forum	Page 9-10
Technology Talk	Page 10

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#### **Interface Gauteng**

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On the 10th of June I attended the launch of The National Disability Portal, an extremely exciting and ambitious project of the CSIR Information Society Technologies Centre (ISTC) partnership with representative group of Disabled Persons' Organisations (DPOs) and the Office on the Status of Disabled Persons (OSDP) in the Presidency.

The National Disability Portal was born out of need identified after an extensive investigation by the CSIR's icomtek into the needs of persons with disabilities in South Africa. The investigation found a dire need for access to information and communications technology (ICT) and all the advantages that come with it, existed. To address this need CSIR's icomtek has devised an Internet

**ICT** technology based networking national and communication system for people with disabilities. The system will be built on open source software whenever possible. It will be a webbased, multi-portal system portals situated with throughout South Africa. including the rural areas. Disability organisations and other stakeholders will be able to upload and download relevant information and data related to disability issues. Anybody will be able to retrieve such information anytime, day or night. Additionally, people will be able to communicate with each other, not only via email, but also by means of web-cams and audio. A Broadband (fast Internet) capability will be available for video conferencing.

Three things really struck me at the Launch, the first being the fact that in certain areas, South Africa is truly a world leader! Something which filled me with enormous pride! I think too often we look to Europe and the U.S.

and don't the See tremendous talent and potential we have locally. We need to start seeing ourselves for what we very often are, world leaders! Secondly, I got a sense of the growing collaboration between all the DPO's. Something which is long overdue, as the saying goes; united we stand divided we fall.

The third thing which was apparent to me was that AAC has truly arrived! All the dedicated efforts of countless individuals over many long hard years are finally beginning to payoff. AAC is at last starting to take its rightful place in society.

I left the launch of The National Disability Portal filled with pride and excitement. I feel there is a lot to be enthusiastic about for persons with disabilities, their families, friends and people working within the disability sector in South Africa!

Martin Pistorius Editor

martin.pistorius@up.ac.za

#### Chairman's report

Since the last issue of our National newsletter the Coordinating Committee held one meeting in the form of a telephone conference. A majority of the committee members were able to participate. Two of our members submitted apologies and we were unable to connect to two members whose contact numbers were "pre-paid" telephones that cannot use the telephone conferencing facility at this stage.

A number of the urgent issues were discussed and resolved. We unfortunately did not address all the items on our agenda and have held these items over for the next meeting. Two of the required office bearers were elected and I would like to congratulate Maureen Casey on her election as Vice Chairman/Vice President and Nicky Eyre on her election as Secretary. I am sure that they will serve our organisation well during their term of office. The one very important office bearer that must still be appointed is a treasurer.If any of the Interface members (preferably from the Gautena area) has a flair for financial matters and is willing to assist us with this aspect of our organisation, please contact us. I believe that we could co-opt such a person onto our committee.

As most members are no doubt aware, the First Regional African AAC Conference that was held in February was a joint venture between the Centre for Augmentative and Alternative Communication and Interface.

Thanks to all the time spent and effort put into the matter by Professor Alant, she has been able to finalise the financial aspects of the conference.

Another joint venture between the CAAC and Interface was our application to the Lottery for funding. We were allocated about 3% of what we had applied for last year. One of the items for which we requested funding was the conference.

A large proportion of the funds received was utilised to pay the difference between the income received from conference fees and the actual costs.

The balance of the Lottery Fund allocation will be distributed between the branches for the building of infrastructure and matters related to the conference. Again, thanks to Professor Alant and Personnel at the CAAC, a joint application to the Lottery Fund for this year is being prepared and will be submitted shortly.

All of the branches are active and are trying to identify the needs of the members so that these can be effectively addressed. If you have a need for something specific to be addressed, please communicate this to the committee in your area.

Rodney Pistorius, Chairman National Coordinating Committee Interface South Africa Cel: 082 8505638 (A/H) E-mail: rodneyp@yebo.co.za

### **Regional News**

#### **Interface Gauteng:**

How would you like a speechless awareness day, where all participants vow not to speak for a whole day? I'm sure that would be an eye-opener for many people! Or how about a documentary on SABC on AAC?

These were some of the ideas, which were bounced around at a recent Interface Branch meeting, ideas which we hope will mature and hatch at some stage, given support. necessary Another aim for Interface Gauteng, which might be closer to realising, is to help create a support network parents amonast Garankuwa. Two of our members are currently visiting parents of children with little or no functional speech in their homes, but we hope to have a joint meeting in Garankuwa in order to link people up with each other and create an awareness of AAC and other resources.

In the meantime, the parent support group at Nuwe Wending is into communication board making and learning gestures! I'm not sure who has more fun, the kids, the parents or the facilitators. It has been amazing to see how parents start to link with each other and put sensitive issues on the table, and support each other in ways professionals often that cannot. We are still open for people to join the committee - still lots of space around the table!

Please contact us on (012) 420 2001, if you feel you would like to join in on this worthwhile cause.

Kerstin Tönsing

#### Interface Western Cape:

Interface Western Cape has been growing in leaps and bounds this year after a "kick-start" at the AAC conference in February. We held our AGM on the 15th of May, which was a great success. More than 40 people, half of them parents or AAC users, attended the AGM. At the meeting we changed our name from "Interface Cape Town" to "Interface Western Cape", thus extending our borders. Graham Clarke resigned as chairperson and Mrs Zoliswa Saleni was elected as the new chairperson. The other people on the committee are: Brenda Allen, Nafisa Baboo, Maureen Casey, Vaughan Cuff, Nicky Eyre, Lezanne le Roux, Graham Clarke. Andiswa Gaika. Veronica Gavu. Cathy Hartman, Diane Hoctor. Phama, Beauty Zoliswa Tew Saleni, Delia and Luvuvo Tvhulu.

We have identified a number of aims for Interface Western Cape. These include parent support, awareness, training and support. Tembaletu School has an active parent and AAC user group, which is well represented on the committee. Parents meet to support each other and share information. They are also planning on making craft items to sell for fundraising.

### **Regional News (Cont)**

Maureen Casey promoted Interface on a national level by speaking on SAFM radio. Tembaletu School visited parliament where Luvuyo Tyhulu handed out pamphlets on Interface. Nicky Eyre has visited a few centres and schools providing information on AAC. A number of children and adults needing AAC devices have been identified and we are starting the fundraising process. We also hope to expand the support and information service by re-establishing our resource office at Vista Nova School.

Training events for the third term include a workshop by Bruce Baker on Minspeak (14 July) and a workshop on Boardmaker (presented by Maureen Casey – date to be announced). Other workshop topics that have been requested include: "Using the Clicker programme" and "Key-word signing". Please let us know if there are other AAC topics you would like training on.

That's about all for now. Watch this space for more exciting happenings under Table Mountain. We would love more Capetonians to join up as members - the more support we have, the more we can achieve!

Nicky Eyre

### Interface KZN:

#### **AAC Study Days**

We were very privileged to have Bruce Baker, the originator of Minspeak® (Minimum Effort Speak) visit KwaZulu-Natal to present a two day seminar.

On the first day Bruce addressed the following topics:

Vocabulary and Language: What words do children and adults really use & how do they use them?

lconicity: Does a picture really look like what it means?:

Navigation,
Sequencing, motor Planning
and Reading: What are the
real trade-offs in AAC?

Minspeak® Unity® How to begin: teaching language and literacy to early communicators

The single overlay advantage for row column scanning: Why do teachers and clinicians think multipage systems are easier for scanners?"

Information about core vocabulary including the fact that there is great commonality of vocabulary usage across different ages and different populations (including those with severe cognitive impairments) and that 78% of vocabulary we use daily comes from a core of less than 400 words and that over 90% of core vocabulary words are noniconic was well illustrated by research studies presented. of the information presented had enormous implications for application of AAC and challenged the way we often implement AAC, particularly with young children. On the second day Bruce presented the Adult Quick learning System (AQLS) that was specifically devised for adults with motor neurone disease but clearly has amazing possibilities for any literate person who requires AAC. An hour's training in the participants system had initial appreciating the statement by Bruce that provided **AQLS** (communication) power in an hour!

The seminar ended with a quick look at a fascinating manual board developed by Gail van Tatenhove based on Unity® - certainly the first manual board ever devised that includes morphological structures.



http://www.vantatenhove.co m/materials.html

# Interface-Kzn announces new Chairman!

Interface-Kzn committee and members extend a warm welcome to our new chairman, Ben Jonck.
We trust that your time as Chairman will be long, happy and rewarding

Margi Lilienfeld

I would like to take this opportunity to introduce myself as the new Chairperson of the Interface KZN Committee.

My name is Ben Jonck, and as a parent of a special needs child I am looking forward to this opportunity to become more involved in an organisation such as Interface.

My wife, Felicity, is an Occupational Therapist, and is also a member of Interface and is currently the Minutes for the KZN Secretary committee. She became interested in the field of augmentative and alternative communication as a result of son's severe communication difficulties. and is currently doing her Honours in AAC through Pretoria University.

Our son, Matthew, is 4½ years old and has multiple disabilities. He has severe cognitive and motor impairments, is severely epileptic and has no functional speech.

We are currently using various methods to help him to communicate, and he attends Pathways Special Needs Centre.

As the new chairperson, I hope to be able to offer a variety of skills and perspectives.

I am a qualified Diesel and Petrol Mechanic by trade, but have been working for the past 6 years for a division of the First Rand Group. Holding the position of New **Business** Development Officer, I like to think of myself as a people person and a team player, who always goes the extra mile to get the job done. At work I pride myself on my attitude, motivation, and customer care skills. I therefore hope to be able to use my skills corporate and resources, as well as my experiences as a parent of a special needs child to add value to the challenges ahead.

Ben Jonck: Interface KZN Committee Chairperson

#### Discovering AAC Workshop

The day workshop, "Discovering AAC", that was jointly hosted by Interface-KZN and Comm-Links at the Westville Campus of the University of KZN from the 8<sup>th</sup> till the 10<sup>th</sup> July was successful and enjoyed by both delegates and presenters. Topics included in the workshop included "When should AAC be implemented?".

communicative competence for individuals who use AAC, the aided and unaided systems used in South Africa, the importance of the method of language encoding used in the AAC designing system. communication boards, beginning strategies, positioning communication, encouraging learning and communication through play, sequenced social scripts, the importance of involving families in AAC, emergent literacy access methods. Therapists, educators, facilitators and a parent attended feedback indicated that the "friendly atmosphere", "wealth of practical ideas in addition to sound theory" and the "comprehensive, relevant and useful handout" were areatly appreciated. Presenters included Margi Lilienfeld, Shelley Tooth, Elaine Byrne and Chris Engels. Philip Susman and Brendan Bowdler Devices South Africa briefly demonstrated the Pathfinder, Vangaurd II, Vantage and Springboard devices before delegates had a chance to have hands on experience with these high tech devices. Lots of light technology presented options were during the workshop and a good balance between presentations and hands-on activities was achieved.

### Regional News (Cont)

Participants confirmed that new viewpoints and insights provided bv the the workshop and all delegates suggested topics further workshops. Topics suggested included "AAC and the child with autistic spectrum disorder", "AAC in Literacy", "AAC with children who are blind", "challenging behaviours, recent developments AAC" and "how to combine ABA (Applied Behavioural Analysis programming) with So watch this AAC". space.....!!

#### Interface-KZN also welcomes Pretty Gcabashe.

Pretty is working for Interface-KZN as a project developer while she completes the practical part of her learnership in project management through the Services seta. One of the initial projects Pretty is tackling is organizing our growing resources into a effective more library. Additional projects include an awareness project.

### **School News**

### News from Pathways Roodepoort

# Reaching for our Highest Potential!

It has finally happened! Pathways Roodepoort opened its doors somewhat unofficially on 10th May 2004 and we have exactly 3 kiddies to start with and we're running 3 days a week - Monday, Wednesday and Friday at the Weltevreden Park Methodist Church in J.G. Strijdom. Although it has taken over a year to open our doors, we are thrilled,

despite only having about R125, 00 in our bank.

The challenge now begins to sustain the Centre and we need as much help as An enormous possible. thank you to Fay Hannah who is running Pathways with no salary for now with only the help of the children's caregivers until we have money to hire properly trained staff. Without Fay's brave commitment, we'd still be only dreaming about Pathways becomina reality. Estelle Brown, our physiotherapist, is assisting Fay in customising special educational and stimulatory programs for each child. Without Estelle's auidance and sacrifice of time we would not have been able to make a start. So, despite lack of funding, everything is going well.

These are the ideas we have in order to try to raise money:

A Fun Walk / Run with a large contingent of disabled sports people involved. Metro Cash and Carry have kindly donated 200 T-shirts which we can give out to participants at this event.

Hold a Benefit Concert for Pathways - Roodepoort but are sorely lacking contacts in the music and publicity industry.

➤ I have the opportunity to climb Kilimanjaro to raise money and need to generate publicity and sponsorship to maximise the opportunity for Pathways - Roodepoort.



We are aiming to have fun projects lined up as fund raisers so that people can climb on board with a enjoy them and smile. Pathways benefit Roodepoort at the same time. We'll also be assisting Centre small Soweto, which is in dire straits and we would like to uplift them while getting ourselves on our feet. Very stuff indeed. exciting



We have not contacted the parents of children who have applied to attend Pathways vet as we feel we are not ready and we will only take the next step in inviting them to join us once we have money and staff. This is why I say that we have opened unofficially, just to make a small start. If we want to do this properly, we have to take it slowly so as not to disappoint anyone in their association with us. It's all about quality for us! The children deserve nothing but the best and once we are in a position to offer them this, we shall have an official opening and our Centre will be filled with children who we will assist in reaching for their highest potential!

Julie Botha Cell: 083 653 5655

### **School News** *(Cont)*

### News from Pathways-Polokwane

Pathways- Polokwane will be joining Mitchell House Preparatory School, a local mainstream school in 2006. Inc1uding our children into a mainstream school is a dream we have had for many years and it is incredible to experience a dream becoming reality. We were fortunate enough to meet some incredible people in Cape Town who have successfully implemented Inclusion programs into their schools. To see Inclusion in action and to discuss the structures place and receive invaluable advice was inspirational. We have made incredible contacts, which we would be willing to share. As part of our inclusion program the children from Mitchell House have been coming to Pathways to join our children in various activities on a weekly basis. Our children have in turn joined their peers on picnics at the new premises. It is heartwarming to see the interaction, which occurs and to witness the natural, uncomplicated way in which it happens. To see all the children playing, communicating and learning together regardless is aweinspiring. At one picnic Kgaugelo was lifted out of her chair and placed on her picnic blanket. She was immediately surrounded by a group of girls. The topic of conversation revolved

around her beautiful red coat, where she bought it and where she thought they could get one. Words cannot describe the pride we felt watching Kgaugelo offering her friends fashion advice. Some things just need to be experienced and we know that there are going to be many, many moments of inspiration.

Sue and Ruth and all at Pathways-Plokwane

### News from Pathwavs-Pretoria

Pathways Pretoria has been blessed with a lot of new children and we are bursting out of our seems (20 children to be exact!!!)

We currently have a sensory stimulation group, 'n preliteracy group and a functional literacy and life skill group. With the help of facilitators we focus extensively on communication and learning of life-skills.

Our dream for the near future is to start a young adult group to facilitate lifeskills and employment skills. You are also blessed with new equipment. We got an adapted bike, walker and crawler to enhance our outside play programme. We have also bought a lot of integration equipment and are waiting for our beam to start with program. Our older group enjoy aerobics twice a week and also does an obstacle course the alternative days because we want to get and keep them moving.

We are looking forward to our next

golf day on the 14th of October and we are already starting to plan our

HAPPY HOLIDAYS

Christmas cards.

All in all we have been very blessed and we enjoy each day at the school tremendously.

Danita Nel



School for The Unica children with autism coming of age this year. After having stated as a small unit for children with autism with 2 pupils, it is now a fully fledged school with 96 learners! To celebrate this very special occasion, they held a concert and carnival. As always, a few speeches had to be made, but these were different. All of the speakers celebrated the fact that we are all unique human beings with unique interests, talents and skills. We are all different, but it is in this differentness, this diversity, that our true strength lies.

Boy! Did the children celebrate this event! From the little ones who sang "happy birthday" and did the chicken-song, to the older ones who did the Hokey Pokey and danced to the

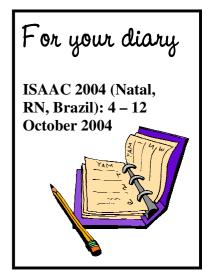
beat of "Meisie Meisie" with their hoolah-hoops and the whistle-blowing brigade, everyone participated.

Some of the learners and exlearners clearly enjoyed centre stage and sang individual numbers and "Bles Bridges" even made a special appearance with one of the boys handing out red roses to the ladies!



Helena Hettema was the quest artist and certainly added to the glamour of the day, and for the grand finale a huge four story birthday cake complete with candles were lit, before hundreds of balloons floated into the air. Congratulations. Christine and all the teachers. learners and parents. May the next 21 years be just as exciting and enriching. As Margaret Golding said, in the end it is all about the "3 P's": Parents: Professionals and Public!

Juan Bornman



### **Aided Language Stimulation Corner**

Spring is approaching again, which means that shortly we'll all be outside again, enjoying the warm rays of the sun on our skin, creating a feeling of well-being and happiness. What does this have to do with the newsletter I hear you ask? Let's see...

When do children learn best? When they are activities. engaged in inspired to learn, when they laugh and when they have opportunities to explore and to be creative. This is a mouthful. How can that be

All of that is possible when elements of fun are woven the learning experiences, making the learning come to life.

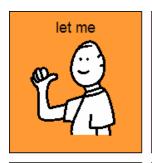
Let's take a well-known activity like making mud pies. Its' an activity that is available and accessible and that creates many opportunities laughing... But do actually learn children anything while they are getting messy and laughing? Well, making mud cakes is actually a science because we are mixing two things together to create something



new. We can also turn this into a creative activity as we can decorate these mud pies with stones, leaves, twigs and other nature items. When looking at it even deeper it can enhance communication

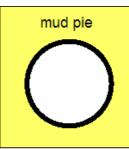
opportunities, e.g. requesting more mud, leaves or water, indicating things like "messy", "finished" and "fun".

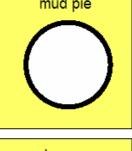
We can even use some mathematical principles as the children can measure the ingredients (e.g. the water), ingredients identify picture/word cards, following steps that explain how the activity should be done. (Some of these ideas come from the AbleNet Newsletter. If you want to see their newsletter, e-mail them at vision@ablenetinc.com).







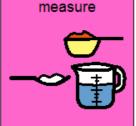




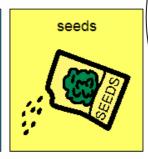








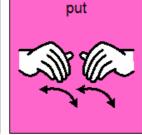








on











AAC Parents. users. educators or therapists can attend a free presentation by the CAAC on services, resources and activities. A demonstration can be given on high and low tech communication aids. Programs are tailored to your special area of interest. Open days take place on a monthly basis, usually on the last Friday of the month, starting at 9h00. If you would like to attend, please confirm with Liza (012 420 2001) in order for us to tailor your program.

Apart from open days to give a basic overview of AAC and the Centre's services, the CAAC also offers consultations to persons with complex communication needs.

In order to schedule a consultation, please contact Mirinda (012 420 4728) or Liza (012 420 2001), Consultations cost R500.00 to be paid on the day of the consultation. We operate on an incontracted fee, so claims can be made from the medical aid.

**CAAC news** 

### **Staff news**

We have the privilege to announce a new member on our staff at the CAAC, Corneli Strydom came all the way from the University of Stellenbosch, Department of Speech-Language and Hearing Therapy. She joined us at the end of June this year. Her responsibilities at the CAAC include training, consultations and ordering AAC equipment.

Unfortunately, we also had to say goodbye to one of our other staff members. Derick Poremba-Brummer. He was an employee at the CAAC as a disability consultant from 1 April 2001 - 30 June 2004. During this period he proved to be a valuable member of the team and assisted in tasks such as training, presenting the value and significance of AAC during open days and administrative tasks. He is still an active committee member and loyal supporter of INTERFACE as well as BIG. both associations for persons with disabilities and their families.

Kitty Uys

### Basic & advanced AAC training

This year's annual AAC training workshops were held from the 21<sup>st</sup> June until the 2<sup>nd</sup> July. The lecture venue was filled to capacity with educators, therapists, parents and students who wished to learn more about AAC - once again we had participants attending from all over the country.

These workshops aim to provide a solid foundation in the basic principles of AAC

from assessment through various intervention issues (i.e. intervention principles, devices switches. and positioning and play) and beyond intervention to legal and employment issues for people with disabilities, as well as the fundamentals of research. Apart from the comprehensive handouts received, the workshop also provided the ideal opportunity for networking with people who have an interest in disability and/or work in the field of AAC - we many people saw exchanging emails and contact telephone numbers

with others.

Highlights of the workshop included a speech by Zach Joubert (on his Delta talker) the practical demonstration of classroom implementation of AAC presented by Danita Nel and Felicia Barrett (from Pathways Pretoria). The participants were also introduced to INTERFACE support group individuals who use AAC and their significant others). Throughout the workshop participants commented that they felt that the information provided was practical and they said they were looking implementing forward to strategies and tips that they had learnt throughout the week. All round it was a very enjoyable workshop for the presenters and staff of the CAAC as well as for the participants.

Michal Harty

#### **Bruce Baker Visit**

Mr. Semantic Compaction (MinSpeak), Bruce Baker from the USA, visited South Africa during July and presented sessions in Cape Page 7

Town. Pretoria and Durban respectively. Bruce included a variety of interesting topics in the sessions, one of which is the difference in the vocabulary used by typical speaking children and adults and the vocabulary depicted on AAC boards and devices. As interventionists we were confronted with the fact that we often introduce symbols or words we "think" AAC users will need in order to cope with situations we predict they will participate in without considering whether it really includes functional and developmentally appropriate words.



stated unpredictability of conversation made it too difficult to plan a core vocabulary for a specific Bruce used the activity. findings of various research studies to point out that most of the words used by speaking individuals are not picture producers (highly iconic), and are therefore quite difficult to depict graphically. This brought up the important issue of iconicity in AAC. Bruce continued by highlighting that speech in general is not highly iconic and suggested that the emphasis of intervention should shift away from the iconicity considerations to learnability of icons.

that will learning plan of the communication Students found this act taking it another step wonderful experience closer to mimicking speech result automaticity will be achieved the which will in turn enhance thoroughly effort.

AAC Conference Johannesburg. him back and recommend visits. that as many of you as We were also extremely possible attend his talks.

Corneli Strydom

### University of Pretoria special and Purdue **University. U.S.A. Exchange Program Commences!**

Our group undergraduate students and visits, such as to the 3 faculty members from Sterkfontein caves, Sammy Purdue recently enjoyed the Marks' house, the Lion Park, wonderful hospitality and and to the zoo. We were so many fabulous experiences lucky, too, to spend 3 days in in Pretoria. We visited for 4 Kruger, where we saw many weeks, from early July to more wildlife than we had August. early completed an program (Special their began with a warm welcome exchange staff and sampled the great Indiana. South African food. Thank you Laurel Becker for

Apart from the language hosting this event. We were be thrilled that our students encouraged by such an joined with a Pretoria special approach, the individual will education class, for which also be able to rely on the teaching was shared by both existing or developing motor Pretoria and Purdue staff. learn about similarities and greater differences in their lives, and Purdue students enjoyed the the overall communication evenings spent with Pretoria students sampling restaurants and night-spots. Bruce is planning to return to A heart felt thank you Mirinda South Africa in February van der Merwe and Dr. 2005. According to Bruce he Annatjie van Vuuren for fell in love with the country adjusting your schedules so when he fist visited it in that we could have the February this year when he integrated class. We hope it attended the First Regional will be possible to organize a in similar shared class in We are educational psychology for looking forward to welcoming pre-service teachers in future

> fortunate to visit some impressive schools such as Zodwa, Unica, New Hope and Edu-plex to observe education inclusion in action. Thanks go to Lien Howatt and Mirinda for organizing these visits.

Despite an intensive schedule of classes we also 6 enjoyed many recreational Students dared to hope.

intensive We hope this inaugural visit of 2 classes will be just the first of many. Education and And we look forward to Educational Psychology) as opportunities to return the teacher gracious hospitality education program The visit received - we hope that the will and braai at Groenkloof reciprocated with Pretoria campus on the first day, students and faculty visiting where we met many Pretoria us at Purdue University in

Helen Patrick



#### **National Science and Technology** Forum (NSTF) Awards for 2003

The CAAC was most honoured to be awarded the winners in the category of "Corporate organisation over the past ten years" at a function in March at Ceasars. The award was made for the contribution that the CAAC has made in training and intervention for people with severe communication problems.

Whilst we are most grateful for the award, an achievement of this nature clearly goes far beyond the CAAC - to all those who so dedicatedly work to make impact in AAC in the

country. In fact what is most rewarding about this kind of recognition is that it is a confirmation that our common efforts are making a difference.

THANK YOU - to all those dedicated INTERFACE members: AAC users, parents and professionals who work so dedicatedly towards impact. It is the small steps that are important!

May this be an inspiration to us all in uniting towards our common goal: to bring AAC to those in need!

Erna Alant



The CAAC has a birdfeeder! It was kindly donated by Denise Mina, who is currently doing her masters degree in early childhood intervention through the CAAC. Prof Alant's office has the best view - to give all involved in the trials and tribulations around the office table "a birds eye view" of what it is like to sit in the



#### Why I'm still on this planet

Hi. I am Zach Joubert. I am 33 years old and stay in Pretoria, South Africa. I am suffering from Frederic's Ataxia, a genetic brain disease, which causes degeneration of the cerebellum and brain stem. As a result of this. I have a serious voice impediment. reduced hand control and poor balance to the extent that I cannot walk without support. I succeeded in **BCom** obtaining а Informatics degree at the University of Pretoria in 1992 before the disease reached a point where my voice was seriously affected. At that stage I could not find work simply because I could not communicate effectively. I could only communicate through my family and some friends. They served as my translators with clients, coworkers or strangers. That same year I became friends with the Centre of Augmentative and Alternative Communication (CAAC) at the University of Pretoria.

After a long struggle to raise money with the help of family, friends and CAAC personnel, I bought a second-hand Delta Talker. At last I had a voice with which I can tackle the "Normal" world!

#### My Friendly Machine

You may ask: How big a problem can such a speech impediment really be? Well, for one thing, I was not independent. Whenever I wanted to go shopping, I had to take along a friend or family member to serve as translator. This is no more a problem. Through the use

of my Augmentative and Alternative Communication device (AAC) I regained a lot of personal independence and freedom. I can choose to whom, when, how, where and about what I want to speak. My days of struggling to maintain my friendship basis or meeting new friends is largely at end. My device is helping me to run my own thus creating business. financial independence.

I have used various communication devices like the alphabet board, an ordinary pen and paper and a small portable typewriter printing out a message letter for letter. These devices are time-consuming and have fallen in disuse due to technical advances made in the communication field.

I still use my Delta talker. It is a synthesized voice-output computer which uses Unity software. Its voice is activated by pressing a combination of pictured keys, called *icons*. You can talk in real-time or pre-record some sentences and trigger them when you need them.

Second to sign language, the use of icons to form phrases is the most common and understandable way of expression by people with voice impediments today.

#### Hello! I'm not a "retard".

The other issue I had to face was people's reactions when I try to communicate to them with my natural voice. Most strangers would either look at me as if I am a creature from some comic strip. Some may even think that I am retarded, joking or that I'm drunk, especially when talking over the telephone with my natural voice. Others, realizing my

handicap, would avoid me by ignoring me. Most strangers who do talk with me, tend to put words in my mouth because they assume I can not make up my own.

Through experience and suggestions by friends and therapists, I have compiled a bag of tricks to avoid losing the other person's attention at the onset of a conversation. For example:

First pre-program your speech device with phrases like "Hi, I am ........ and you?" or: "I am using a speech synthesizer to communicate, so please hold on while I am typing!" or "I like to add something to the discussed point, please wait while I'm writing it."

Secondly. learn how to operate your speech device at as fast a tempo as you can. It must be very frustrating for non-AAC users to wait for an AAC user to finish spelling each sentence. I am a big sinner of this rule, but I am learning it as fast as possible. For me. communication is not only a social necessity. It is also imperative for making a living financially; in my case: running a business. Let's take an example of a coffee shop: Each customer has his/her own preference of how strong or hot the coffee should be. How does a waiter/waitress determine the individual preferences each customer? The answer is through communication with the customer.

#### Mr. Universe, here I come!

I often asked myself: 'Why did it happen to me?''. Through trying to come to terms with my handicap, I came to understand and become interested in the

process of communication.

I have become involved with speech disability awareness campaigns. I also inform other people with complex communication needs on how to gain funding for- or access to AAC-devices. I have become a member of the International Society of Augmentative and Alternative Communication (ISAAC) and of Interface - South Africa.

I am also a member of the ACOLUG listserve, where you can find out everything about Alternative and Augmentative

Communication; tips and tricks of using AAC's and above all meet people with the same interests as yourself. Check it out at <a href="http://disabilities.temple.edu/acolug/">http://disabilities.temple.edu/acolug/</a>

One of my life's highlights was attending an ISAAC conference in Odensa. Denmark in 2002. The conference was about seeing what people with disabilities, like myself, have managed to achieve by using their assets and talents to overcome physical and mental barriers. People whom society writes off, marginalizes. ostracizes. People whom society puts in nursing homes to be 'cared for'. It was an absolute eyeopener as to what can be achieved.

Yes, of course we think: That's the States, or those are rich first world countries. What particularly struck me was that a lot of the challenges that we are facing here in South Africa, are the same in other countries. Negative attitudes towards disability resulting in marginalization

### **User forum** *(Cont)*

and little funding: It's world-wide. I realize how important it is to start talking to other people — ask them what solutions they have found and learn from each other.

The financial burden that AAC users place on society can and is being reduced if all interested parties, e.g. AAC users. friends/family, and professionals work together on future developments and studies in the field of AAC. As an AAC-user myself. I feel that we, AAC-users, have the responsibility to show society what benefits there might be in helping the AAC-users develop their full potential.

I intend to attend the ISAAC conference at Natal, Brazil in 2004, not just as a spectator but as someone who can help others who could copy some of my life's perspectives.

My vision is that public awareness and the exchange of ideas in support of ongoing research in the field of AAC *today* will ultimately result in the common availability of hitech Speech synthesizers and a friendlier social environment to use them in.

Zach Joubert

#### Thoughts of Tomorrow

A tranquil thought, or three
Warm permanence and solidarity
A constant Pal on this epic journey.

By Kevin Hollingshead

I watch you move, I hear you talk and yet my limbs don't want to walk. I move my mouth to let you know and yet somehow the words won't flow. I watch your face to test your mood, perhaps you think me very rude.

But I have thoughts and feeling too, if only I could talk to you. To tell you Oh, so many things, the joy I feel when I hear you sing. And then if only I could explain, the pains and headaches I contain. I shout and rage to make it clear, but it all falls on stone deaf ears.

Oh Dear, here comes that horrid man. You know?

The one who tries to plan and whispers too, those dreadful things, he bids me do. But you insist he's not there, when all the time he stands and stares. I try so hard to shut him out. Why can't you see, when he's about?

I want so much to be like you. To laugh and talk and play the fool. To understand and be understood, like everyone in this world should. But perhaps, I'm sent trapped in this frame, to teach mankind a simple game.

That love and patience, strength and trust, you all can learn, by helping us

#### By Joan Scott Allen

### **Technology Talk**

#### **Using Eye-gaze frames**

Eye gaze or eye pointing is often used by children who severe have physical disabilities and require AAC. Young children often spontaneously use eye gaze with their caregivers as eye gaze is a motorically easy selection option. Even when children are able to use a switch and scanning or other methods of AAC they often become fatigued and then eye gaze can be used as an alternative option. . It is also a very useful for when a child is given a more cognitively taxing task and one wishes reduce the motoric demands or in the situation where one quickly wants to offer choices or resolve a communication breakdown. We have found using eye gaze frames far easier than using E-Trans. communication partner looking through the frame from behind can readily see where the child using AAC is looking. Other advantages include portability and they can be used with the child in any position e.g. even when the child is lying down.

For effective use pattern we want to teach the children is follows. They need to look at all the options (represented photographs, picture symbols, letters words etc.) and when they are ready to give their message or make a choice, they must look through the frame and make eye contact with communication the partner. Now they must look at their selection and look straight back making eve contact again. In this way there can be no doubt as to what they have chosen. Frames made Comm-Links are available from Interface-KZN at R 40 per frame. They frames are made from lightweight plastic tubing with adhesive Velcro already attached (reverse of frame can be used with press stick).

Margi Lilienfeld



Interface KZN - 031 7011 444

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Your contribution will assist Interface and the CAAC in helping parents, children and other AAC users to face the great many challenges encountered on a daily basis

### Let's work together to make a difference.

YES! Count me in as a support of Interface / CAAC in 2004. I would specifically like to support:

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