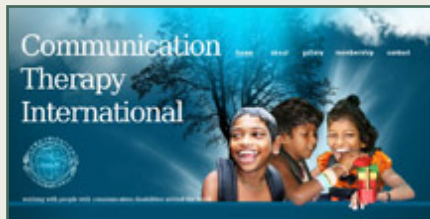


# Communication Therapy International



cti.newsletter@yahoo.co.uk  
News Letter July 2009

An organisation for those working with people with communication disabilities around the world



The CTI website [www.commtherapyint.com](http://www.commtherapyint.com)  
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all of you! Another year has gone by. Although we do try to produce a newsletter twice a year, this is a bit of a struggle

as I don't get enough material sent in by you lot to make it worth the costs. You will have received our lovely study day report earlier in the year though, and we'd be pleased to get feedback from you about that! Please let me know that you are out there! We know you are



We currently have about 150 members. Many of them are Speech and Language Therapists or Specialist

Teachers who are working in remote areas where services are just developing. Some work with CBR programmes, some in schools, universities, disability/rehab centres or hospitals. Often they have a training role, passing on skills to others working with communication disabled people. We also have some parents, health professionals and community workers in our ranks. However we are an open organisation and welcome members with any background who have an interest in working with children or adults who have communication disabilities, particularly in rural, remote or under-resourced settings. We aim to exchange information and support each other in working in areas where services are just developing or are scarce.

## Our next study day coming soon!

### The topic>

Sustainability in Disability Projects

**The date>** Saturday November 15

### The Place>

Institute of Child Health, UCL London

### For more inf

Linda Watson at

[ctimembership@yahoo.co.uk](mailto:ctimembership@yahoo.co.uk)

## New this year! CTI Advice pack

Earlier in the year we held a workshop to write a pack of advice sheets which we hope will be helpful for people who are planning to go and work in communication disability projects outside their own region or country.

This will be distributed in electronic or paper form free of charge to anyone who contacts us. We are often contacted by people who are thinking of going to work on a project in another country, where they will not know the culture, language, or the way that disability services work.

The pack consists of 5 sheets of ideas on different aspects of preparing to work outside your usual setting, and how to make this successful and sustainable. Of course it doesn't provide answers but is designed to make people ask the right questions of themselves and their host organisation before they embark on a new project. The pack will be launched at our November meeting and will be available after that. If you would like an electronic copy please e-mail us.

## African regional group link

After discussion over many years about trying to form some regional groups within CTI, we finally have the beginnings of the first one.

Delix Missinzo who is in Malawi has agreed to act as the link for members in Africa. We hope that in time this may even lead to regional meetings, but of course this is up to you the members to organise. Do get in touch with Delix to let him know about your work if you are in Africa.

Mr Delix Missinzo

Mountain View School for Deaf Children, P.Bag 16,  
Bvumbwe, Malawi

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## ISAAC – 'emerging nations'



The International Society for Alternative and Augmentative Communication ISAAC have just held their latest Symposium in Montreal. Much of the

conference focuses on high tech approaches to providing augmentative and alternative communication for people who have little or no natural speech. However they do also have some members from 'emerging nations' and under-resourced regions where solutions probably need to be low tech. There is a group within ISAAC who are interested in these issues and there were some talks which suggested ideas that would be relevant in a variety of cultural contexts.

There is recognition that even when someone has a high tech communication aid, they often use other alternative means of talking more of the time. Thus we need to think about ways to encourage and develop symbol and signing systems to suit local cultures and to make sure that when we are doing training with teachers, CBR workers etc we emphasise the importance of recognising and making the most of people's non-speech ways of expressing their wants, needs and feelings. Using locally drawn and produced symbols and pictures is really important and these will then be easily understood, culturally sensitive and appropriate. It's good to find a local person who is good at drawing to help you if you are developing a set of symbols for someone whose culture you don't know well.

ISAAC are planning to make stronger links between people working in 'emerging nations' and CTI are hoping to help with this through our membership. So if you would like to be

involved in this do let us know and we'll pass on your info.



If you want to know more about ISAAC you can find them on

<http://www.isaac-online.org>

## October is international AAC Awareness Month!

For more information, visit:

<http://www.aacawareness.org>



*"In our last edition we had an article about the new SLT degree programme running in Bangladesh written by Cristy Gaskill who had been teaching there. This time we have a follow-up from one of the students on the course. Over to you Sharif:-"*

I am a final year student in the B Sc in Speech and Language Therapy program at the Bangladesh Health Professions Institute (BHPI). BHPI is the academic institute at the wellknown Centre for the Rehabilitation of the Paralysed (CRP), and is affiliated with the University of Dhaka. My classmates and I will graduate in December, 2008, as the first Speech and Language Therapists in Bangladesh.

The World Health Organization has estimated that 10 percent of the world's population has a disability, which means about 14 million people in Bangladesh. Within Bangladesh, people with complex communication needs have very limited access to Speech and Language Therapy services. Speech and Language Therapists aim to improve people's quality of life for those who have speech, language or swallowing difficulties. Bangladesh is a developing country, with an emerging health field. That being said, there are still no qualified Speech and Language Therapists. I firmly believe that communication is everybody's right, and is critical to facilitate equal participation as valued members of a community.

The curriculum for our programme was designed by two UK SLT lecturers and is based on the course in Sri Lanka which has been so successful. Our program consists of four years of teaching and placements, followed by a one year clinical internship.

As a final year student I am doing a dissertation on Alternative and Augmentative Communication (AAC). I am looking at the perceptions and attitudes that may impact successful communication for clients using AAC systems. This is a very new field in Bangladesh, and is difficult to research as there hasn't been any prior research in this area, and because there are limited academic resources available. I was lucky enough to be awarded the Shirley McNaughton Exemplary Communication Award by ISAAC, so was able to go on a three week internship in Canada, followed by the ISAAC Conference in Montreal. This was a great experience.

### Our clinical work

According to the curriculum, students need to do a minimum of 650 hours pediatric experience and 350 hours experience of working with adults, in total approximately 1000 hours. Of course this is difficult to organize when there is no established service already existing. Very often we students

are involved in setting up services at the same time as learning to be therapists! Students also need to visit community placements related to the subjects they are studying, as well as neurology, ENT and paediatric clinics and additional disability/specialist centres as available.

During placements, SLT students have seen many clients and many people have come from far away in other parts of the country. Students can only provide a basic service at this time. Still we have lots of people on the waiting list to see us. In Bangladesh, most people think that the therapist will use fantastic equipment for therapy and client will speak spontaneously. This is hard to manage sometimes.

Because SLT is very new in Bangladesh, all of our teachers come from overseas as volunteers, and teach us in lectures/classes and give us support as placement supervisors. Sometimes there are enough volunteers to teach us and sometimes there are not. This is a problem for us. When there are not enough qualified SLTs around the students face many problems (supervisor supervising many students at a time, class schedule changes, etc), but all the teachers try very hard.

12 students get a chance to start on the course each year. Currently, there are 4 batches continuing. My batch who were the first, are now in the final year and we are doing our dissertations on different topics. After we graduate in December 2008 we will do our internship at CRP. Because SLT is very new and growing, currently it is very demanding profession in Bangladesh, as often we will have to set up services and work on our own. Already, my fellow students are getting job offers to work in different places (international & national NGOs, private clinics & hospitals, special education units, rehabilitation centre, mother and child care unit, etc). This is really exciting, as we will be able to start to provide a proper service for disabled people in these different places.

Md. Sharif Al Mamun

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The Centre for the Rehabilitation of the Paralysed currently have a great need for Speech and Language Therapists/ Pathologists who would like to assist with training students, supervision of clinical placements and establishing clinical services. They are seeking people with a range of interests, all levels of experience and for variable lengths of time.

To discuss further please contact:

Md Mostafa Zaman

SLT Course Coordinator

Email: [slt-bhpi@crp-bangladesh.org](mailto:slt-bhpi@crp-bangladesh.org)

CRP website: [www.crp-bangladesh.org](http://www.crp-bangladesh.org)

### New Cleft Lip and Palate Book Out now!

Management of Cleft Lip and Palate in the Developing World. Published in 2008 Edited by M Mars, D Sell and A Habel.

Pub Wiley-Blackwell  
ISBN 978-0-470-01968-9

This is an unusual book because it deals with one specific condition and the treatment, management and impact of this. One of its strengths is that it is multidisciplinary, so it considers cleft lip and palate from many different points of view and emphasises how important communication and collaboration between team members is. It is aimed mainly at people who are planning to set up new cleft services in places where resources of materials and manpower are limited. Interestingly it also includes chapters from NGOs involved with cleft work and some discussion about both impairment focussed work and the disabling impact of cleft lip and palate on the person and their family. A great resource if you're involved in this kind of work!

## The New Directory is out but we still need all of your missing e-mail addresses!

With this mailing you will have received our new members directory, which we usually update every two years. However this is an expensive exercise and we have no funding except membership fees to pay for this! Next time we would like to move to an electronic form for most people. You will notice that we have e-mail addresses for some people but not all. If we do not have an e-mail address for you or your details in the directory are incorrect PLEASE let us know. As a networking organisation this resource is our most important document. People can't get in touch with each other if the information is inaccurate. Please e-mail Ruth Patil if you need to update us.

ctimembership@yahoo.co.uk

## Rehabilitation International (RI) Quebec 2008

RI is a global and diverse organization bringing together expertise from different sectors in the disability field, advancing and implementing the rights and inclusion of persons with disabilities

It is a worldwide umbrella organisation with organisational and individual members in many countries with many different perspectives on disability. There are many professionals, NGOs and Disabled People's Organisations involved.

I (the editor Mary) was lucky enough to attend their conference in Quebec in August and I found a number of sessions were of interest to those of us with concerns about disabled people in under-

resourced regions.

There were several sessions discussing aspects of CBR (Community Based Rehabilitation) and how well this works, what needs to be changed to enable this approach to do an even better job. There was of course lots of discussion about how CBR needs to be a flexible strategy which can work in different ways in different places. However there is still a feeling that it needs to strengthen its work in advocacy and empowerment of disabled people, rather than just focussing on provision of impairment based services and rehabilitation.

Representatives from the Disability and Rehabilitation Team at WHO (World Health Organisation) gave us some information about the new CBR guidelines which are currently being developed. These will be published in 2009 and their aim is to clarify the aims and objectives of CBR and suggest some ways in which can be implemented. Some members of CTI have been involved in the drafting of aspects of this document, in particular the section on communications. We hope that this will be a useful resource once it is published next year

## New WHO Wheelchair guidelines launched

Also at the RI conference, was the launch of a new book of very comprehensive guidelines about wheelchairs and how they should be designed, fitted and provided for people who need them in under-resourced settings. This was a great example of collaboration between a number of agencies who had come together to agree about what works best. You can order the full book from WHO or you can download it in English or French from

<http://www.who.int/disabilities/publications/technology/wheelchairguidelines/en/index.html>

Also of interest to CTI was a talk by Barbara Collier about the work of the organisation ACCPC (Augmentative Communication Community Partnerships – Canada).

The organisation fosters full citizenship for people who have communication disabilities. One of their main concerns is the safety of people who are communication disabled and use AAC. Their research shows that people with communication disabilities are at increased risk of all forms of abuse. Disabled people are generally known to be at greater risk of abuse, which they have little power to control or avoid. Often this occurs in familiar or home settings and 'most offenders are persons in positions of care and trust' (Pointing it out leaflet). ACCPC have produced some very good publicity and training materials on this issue. They suggest and organise training for disabled people themselves and also for parents, paid carers and other professionals. Although the examples and focus is north American, this issue is almost certainly an important one in many countries globally and for many disabled people, particularly those with communication difficulties and of all ages. Their materials may be useful to you and colleagues in other cultural settings, with some adaptation of the pictures, and language.

For more info see their website

[www.accpc.ca](http://www.accpc.ca)

## UN Convention on the Rights of People with Disabilities.

As you all know this very important convention was adopted by the UN in 2006 after a great deal of hard work by disabled people and others. So far about 136 countries have signed up to it. Are you in a country where it has not been signed? Are disabled people where you are aware of it and the rights it should help them to achieve? What do you think it will do to

help people who have communication disabilities in particular? Let us know your views and experiences for the next edition of the newsletter!

For more info on the convention see

[www.un.org/disabilities](http://www.un.org/disabilities)

### It is International Day of Persons with Disabilities on 3rd December 2008!!!!

The theme is :

**“Convention on the Rights of Persons with Disabilities: Dignity and justice for all of us”**

You still have time to organise an awareness-raising event on this day. Do let us know if you do and how it went!

*Setting up a Communication Disabilities Service in Ghana*

**A report from Nana Owusu who is an SLT from Ghana**

#### Background

*“The idea to start a communication disabilities service in Ghana was sown sometime in 2004, after my MSc Speech and Language Therapy training in the UK.”*

I had developed a special interest in exploring ways in which people from African backgrounds living in the UK, in particular, could take full advantage of all the different

approaches and advice offered to parents of children with communication disabilities. In the UK, for younger children, play was an essential means by which most of our “treatment” was done. Yet, for many families from African backgrounds, play was not really understood as something which could help children’s progress. My MSc project looked at play in ten West African and ten White British families. The findings confirmed the lack of understanding of the value of children’s play in building up their communication skills among families from West Africa.

Using English only, instead of one’s own language was another issue. Many African families were reluctant to speak their own languages to their children even when the parents’ English was not proficient enough. Children’s vocabulary was not developing as well as it could because parents’ English was not strong and many lacked naturalness in speaking English. Often immigrant parents from countries where SLT was established were quick to take up the service being offered in their new environments. In addition, many families from European countries were more likely to talk to their children in their own languages unlike many families from African backgrounds.

From 2004, I started investigating some of the above questions when I was visiting Ghana. I visited schools and talked to teachers. I used contacts I had with people I knew in the teaching and health professions to find out what was available in the public sector. I decided in 2005, to take a six months career break from my work in London and travel to Ghana to conduct a mini study into the provision of service for children with communication disabilities.

The study aimed to find out what happens to

children with communication disabilities and their families: Where did children and their families receive help and what were the main presentations of difficulties? What did health, education, voluntary sector and the general public know about communication disabilities? What were the influences of cultural/traditional beliefs and how did their practices affect the delivery of a SLT service?

Participants were paediatricians, ENT doctors and nurses, audiologist, audiology technicians, public health nurses, psychologists, Early Years Childhood Development Centre Providers (ECDC), primary school teachers, parents and carers.

### **Methods Used**

A number of different methods were adopted to help gain a broader spectrum of responses and information. They included the following:

- Questionnaires and individual interviews with parents, health and education professionals,
- Attendance at ECDC executive, general and zonal meetings,
- Attendance at PTA meetings
- Conversations with parents at the Korle Bu, teaching hospital, Children’s Block and the Audiology Centre,
- Visits to schools and discussions with principals and early years staff.
- Offer of an advice clinic once a week for six weeks at the ENT department of the Korle Bu Teaching hospital
- Offer of private assessment sessions at a private clinic.

## What Service?

The study clearly showed that parents and professionals together felt that the need for a communication disabilities service was overdue. Travel and access to the internet, had increased people's knowledge and understanding about various disorders and conditions. Both parents and practitioners knew something could be done but often did not know what and how. The findings suggested that a service in the community would be the best option to address the situation in Accra at the time. Meanwhile, the ENT department wanted me to be attached to their department and although it was claimed that I would be available to the whole hospital, I knew that this would be difficult in reality. For more than five years, the ENT department had had a SLT, but he was known only to that department and a handful of doctors in the hospital. During my study, some health workers were quite surprised to hear that a SLT had been working there!

### Challenges faced in planning a service

It was evident that the most appropriate service would be based in the community, in order to do assessments and offer therapy, and also to provide some school outreach support to teachers and the children attending mainstream schools. Later, special centres for specific disabilities (e.g., cerebral palsy, autism) could be developed to provide a more tailored service and approach. I did not believe that a service based at the hospital was the best option at the time. This was partly because all the referrals, with the exception of 2 out of 33 during my volunteer time at the hospital were out-patient cases. With the exception of perhaps two adults, none had undergone any surgery so did not need to be seen in a hospital. The referrals were mostly children with developmental problems

from the community, so it did not seem necessary for the service to be medically based.

I felt that before a hospital based service could be started, doctors and nursing staff needed to undergo training and awareness-raising to educate and inform them on the role of the SLT. They would need to know about working together with other health workers, understanding how, why and when to refer to SLT as well as about realistic expectations for clients. Without all this preparation I imagined a SLT service with mostly out-patient cases and no multidisciplinary way of working to ensure effective input. I was also aware that many people thought that SLTs somehow had special powers to squeeze talking out of anyone who had a difficulty! The ENT doctors' strong desire to have an SLT service in the department was partly to fulfill the condition of developing the department as a facility for training ENTs. It was therefore my view that the need to set up the service was not really client-based but part of an ambition to raise the profile of the department in the country and the region. After the study I informed the ENT department that the greatest need was in the community and there was no reason for clients to come and choke the system in the hospital for SLT. Trying to run language groups or individual sessions with screaming children and no play area was definitely not an attractive option. I felt that the best option would be a part-time arrangement to maintain a presence and gradually raise the profile of SLT within the hospital while developing alongside it, a community based service and have people trained to work there. In that way we could provide help to a wider range of people, as well as raising awareness of communication disabilities and so increase the referrals to SLT from professionals and the public. Unfortunately however this did not go ahead because the

Ministry of Health did not allow or encourage part-time working.

Sharing findings with Special Education Division (SPED)

SPED has responsibility for providing special education for all children with disabilities in Ghana. However, SPED has focused on 3 areas of disability; vision, hearing impairment and 'mental retardation' (learning disabilities) and although there is some awareness of other types of disabilities, not much is done to support them. There was not much support from SPED to develop a service for people with communication disabilities and in fact, some SPED workers advised me to set up my own organisation and recruit them to work with me. SPED was more interested in proposals that could be backed with money because they did not have funds to consider new projects.

## Private and Non Governmental Organisations (NGOs)

After these unsuccessful discussions with health and education, the only option was to set up a service independently. I had already teamed up with an audiologist and started some private speech and language therapy services to those who could afford it. However, it was clear that the majority of people were unable to attend for extended therapy because of the costs. Often changes in clients' communication skills are small and do not happen immediately. This was often difficult for parents to understand as many wanted immediate and very obvious improvements or cures (miracles!) . They may not continue to bring children for therapy if change was not obvious and therapy over the long term would be too expensive.

Many of the referrals for the private practice are from the expatriate community who already have knowledge of SLT or are more receptive to it generally because the service is available in their country of origin. They may have had more exposure to ideas about play, therapy and about work with disabled people often being about improving functional skill not about 'cure'. 'AwaaWaa2', the NGO was therefore set up to cater for the many children with communication disabilities who cannot afford the charges of a private practice. Funding for AwaaWaa2 has been mainly from the private practice and 'Friends of AwaaWaa2'. These are individuals who are convinced about the vision of the organisation and feel pushed to support it. AwaaWaa2 in addition charges a small fee as well as fundraising for sponsorship to run its programmes. Parents have welcomed the idea of paying something for a service they need. Some parents pay more and this helps to make up for those who cannot afford to pay at all.

AwaaWaa2 has now teamed up with 'Autism, Awareness, Care and Training' (AACT) to provide therapy for children with autism. With my experience and training as a SLT, I am able to help them structure and monitor programmes for the children as well as develop and run specific groups for their two centres. I refer children to the AACT for appropriate support and we are able to share information on children who are common to us. An AwaaWaa2 staff member works together with AACT staff to facilitate the autism group. I believe that this arrangement benefits parents and the children, as the family only have to go to one place, reducing travel time and costs. This joint approach also provides better consistency for children who are already at AACT. We are thinking of running all autism groups from AACT. This is great teamwork and we share

our skills!

AwaaWaa2 is also developing a group for school aged children with language delay/disorder with Special Educational Needs Drama-therapy Centre (SENDRAC), an organisation for children with learning difficulties. AwaaWaa2 will develop the programme and help set it up with a member of its staff as one of the facilitators in the group. We are now looking for similar opportunities to set up services in different places so that more children can benefit and hopefully have less distances to travel. We have also had various requests to provide training to teachers and parents.

## More Challenges

The apparent progress has not been without some challenges. These have been many but here are the main ones:

1. Referrals – Many referrals have come as a result of relationships we have made e.g. through active participation in Early Years Childhood Development Centre programmes and meetings over some time. Referrals also come from one Neuro Paediatrician who has a good understanding of multidisciplinary working and who has practiced in the UK. However a system for written referrals and for written records or reports is not in place and this makes information exchange difficult. This is of course common in many newly developing services. Many health and education practitioners are still not used to the new service and need ongoing support, information and training in order to know when to refer clients to SLT.
2. Distances – Families travel long distances to access the limited service. This often puts people off from attending therapy regularly. Travelling on busy public transport with a child with tricky behaviour, is hard work! People often miles across the country for help and the service needs to adapt to provide help for families coming such long distances.
3. Resources – Unless it is a government funded organisation, obtaining funds to train staff and run the project can be extremely difficult.
4. Lack of joint/collaborative working – Working together across professional boundaries can be difficult and is unusual. There is much duplication, work which is ineffective and often people are working in isolation because there is often no culture of sharing and combining strengths to achieve specific goals. However, with money or abundant resources it is always easier to get others to work with you.
5. Spiritual/Cultural Beliefs, Practices and Attitudes. - Belief in God, spirits and a power much greater than the individual is common and can be helpful or harmful. This impacts very much on how people live their lives on a daily basis. There are many beliefs about people with disabilities, mostly negative and this stigma also applies to the person who has conceived, carried and borne that child. In many cases therefore, therapists deal with parent's (invariably the mother) emotion in addition to everything else. It is often suggested in informal discussions that nondisabled people must be helped before people with disabilities. This gives the impression that people with disabilities are second class citizens and must be pitied. Many times I have heard well educated people remark about a deaf person 'oh, and she's such a pretty girl'. In Ghana there is no

state pension for retirement, so people traditionally invest in their children, who they expect will look after them in old age. With limited resources, however, many parents find it hard to invest in a child with a disability especially if progress does not promise to be swift and a cure is not immediately in sight.

6. 'Beautiful' official policies versus lack of implementation – On paper, there are many 'beautiful policies' which if implemented could spell positive changes for people with disabilities. Frequently policy makers and practitioners as well as government representatives who act as signatories to universal guidelines work in isolation from each other. Often there is little co-ordination or collaboration on what is practical and appropriate for the country and what needs to be the priority.

## Some lessons learned and practical tips!

It is essential to carry out good groundwork on what is already happening and establish a network with relevant stakeholders and practitioners before deciding on setting up a service. Insist on a written outcome of any investigations done to help you make the right decisions. Once you have evidence of the need/demand for the service, it is easier to convince yourself and others that it is right to start something, however small. Find and develop close links with organisations that have similar objectives and vision. Collaborate with them, especially, when raising funds, awareness and informing / educating the public on who the services are for. Usually the initial emphasis has to be on giving people information and training to understand about communication disability. You may need to focus on attracting funding to provide training for a few people to help you, especially in the initial stages of the organization, so that

a basic service for clients can get going.

It is important to be flexible and ready to make changes to your plan as you embark on the practical work of establishing a service. For example, AwaaWaa2 has included an outreach service to schools as part of its brief, when this was not a major part of the original plan. However, with long distances families travel, we feel we ought to visit and support children in their school environment while using the opportunity to inform and educate teachers on a child's disability and how they can help them. When there are only a few highly skilled people in a country, you have to focus on passing on your skills and knowledge to others who can help the clients.

You will need to develop close links with nurseries and schools that you have prepared to accept children with communication disabilities. In Ghana and possibly other parts of Africa, keeping a child with disabilities in mainstream can be an almost impossible job for parents. Often teachers and other incidental staff do not know how to support these children which often means the child suffers and is either withdrawn or left to his own devices in school or at home.

In Ghana, and perhaps other places, setting up a service without support from government is extremely difficult but it is feasible. Waiting for government support before setting up a service can be a long wait, with nothing tangible being offered to disabled people in the meantime. Many people have learned that the best option is to start something small on your own, an NGO or private practice. Once that develops well, the government will seek you out to assist in the development of similar programmes.

Nana is happy to have long or short term visitors to Ghana to help with her work. Contact her directly on

[nanaakuaowusu@yahoo.com](mailto:nanaakuaowusu@yahoo.com)