

DbI Review

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Deafblind International was formerly known as the International Association for the Education of Deafblind People. DbI Review appears twice yearly, the two editions are dated January-June and July-December.

The editor will be pleased to receive articles, news items, letters, notices of books and information on forthcoming events, such as conferences and courses, concerning deafblind children, young adults and older people. Photographs and drawings are welcome; they will be copied and returned.

All written material should be in the English language and may be edited before publication. It should be sent for publication to arrive by the date below.

Opinions expressed in articles are those of the author and should not be understood as representing the view of DbI.

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Cover: Communicating at the Perth conference
(Courtesy of Sense's Foundation Inc.)

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A message from the president

Dedicated to the memory of Mike Collins.

Truly a great, gentle giant of a man. Many of us still have a problem coming to grips with the loss of this dear friend, even though he is certainly still with us in spirit and reflected in many of our activities and developments. In fact, many of the actions under way have been initiated or supported by Mike. His contribution to the well-being of deafblind children, adults and their families, our organisation and membership has been of huge importance.

Mike has always insisted upon the importance of collaboration at an international level with all organisations and agencies within the field of deafblindness. As a matter of fact, he was very active in the creation of the Memorandum of Understanding (MoU) with ICEVI, and we are finding practical areas for co-operation. Following up from this, recently, we have signed an MoU with The World Federation of the Deafblind at the meeting in Zagreb of leading organisations in Europe of/for Deafblind people. We investigated areas of communication, interaction and future activities together.

The development of the strategic plan is well in hand, the proposals have been ratified, and people have volunteered and been identified to carry out the individual tasks to be undertaken. I would like to thank those who have kindly offered their time and energy to ensure that Deafblind International can grow and develop. Mike was instrumental in the first working group some years ago that was set up to investigate the thoughts and reflections of our members on how they would like to see the future of Dbl. This was a milestone and very important to where we are today.

The influence of our dear friend and colleague can be felt in everything we are working on at the moment, but I would also like to mention some specific developments in the last year or so.

By the time you are reading this, we are in the process of finalising the handover of the secretary and secretariat functions, we had two fantastic bids for these really important roles. This made our choice extremely complicated and, after careful evaluation, it was decided that Senses Foundation, in Perth, Australia would be given the task. We all look forward to a fruitful relationship with our new secretary and secretariat. I would like to take this opportunity to thank Sense International for the wonderful support they have given to us over the years. To ensure the quality of transferring the office successfully, I would like to thank Sumitra and Sense International, India, for undertaking a heavy programme of work to ensure a smooth transfer.

As always, we are extremely grateful to our Networks, and in particular, the organisation of the three major events taking place in the autumn, where I hope many of our members will have the opportunity for in depth discussions on priority themes. I hope to see many of you there.

Another Dbl activity which gives me special pleasure to invite you to is the European Conference planned for September 2009 in Italy. I have been living in Italy now for 20 years, and from past experience of international events organised here, I am sure that it will be an exciting and beneficial experience for all.

As a final note, as you without doubt know, Tony Best is in the process of leaving Sense for a new professional challenge. I am sure you all will agree with me, in thanking Tony for his constant support for our organisation. We wish him well in all his endeavours and future. Somehow I have the feeling we have not seen the end of Tony in our field, probably a new small corporate could emerge!

As always I would like to thank all of our membership, network leaders, management committee, council and all who contribute so much in their leisure time, to our organisation and, in consequence, to deafblind people and the significant others in their lives.

William Green

The importance of having ‘Good Taste’

The power to change the lives of persons with deafblindness around the world

David Brown, from California Deafblind Services, continues his very successful series of articles about the senses and how they interact

Taste (the gustatory sense) is the sense that drives our appetite, and also protects us from poisons. The senses of taste and smell are very closely linked, although stimuli through each of these senses travel by very different neurological routes to reach the brain and provide information about environmental events and factors. Previous visual, auditory and tactile experiences can become powerfully attached to certain taste sensations and memories, and can stimulate strong taste anticipatory expectations. The taste receptors, located in small areas called taste buds, are distributed throughout the mouth, right down to the oesophagus. The tongue has the most of these receptors, about 65% of them, but the rest are distributed over the epiglottis, the soft palate, and the laryngeal and oral pharynx. The taste receptors are sensitive to chemical stimulation provided by food substances dissolved in saliva in the mouth. Many nerves are responsible for transmitting taste information to the brain, and because of these multiple neural pathways a total loss of taste is very rare. Alongside distinctive and identifying taste information (for example, tastes that we might refer to precisely as ‘banana’ or ‘coffee’ or ‘Parmesan cheese’), there are less specific and more generalised aspects of taste sensations (those responding to stimuli from the skin surface such as stinging, burning, and chilling) which can be induced by many foods through the trigeminal nerve (the fifth cranial nerve) in the tongue and the oral cavity. Facial palsy results from trigeminal nerve damage so is likely to involve some compromise to the full and effective sense of taste. We know that in the population of children with CHARGE Syndrome, for example, about 43% have damage to this fifth cranial nerve, which must present an additional, taste, difficulty to their other challenges with eating and drinking. Infants experience taste sensations before birth as the first taste buds appear at about 8 weeks gestational age, and a foetus sucks and swallows up to 1 litre of amniotic fluid every day, so at the time of birth a functional sense of taste is already well-developed. Newborn infants have a high level of discriminatory taste because they have a great number of taste buds (about 7,000), and the number actually continues to increase for a period after birth. But the effectiveness and the number of the taste buds decreases with advancing age, so that a 60 year old person probably has only about 2,000 of them remaining. You may have experienced older people complaining about the increasing blandness of foods and needing more salt or spice or sugar in their meals to stimulate their taste

buds. Certain medications can be responsible for taste loss and should be reviewed in any child suspected of having disturbance of the sense of taste. Excessive dryness of the oral cavity, for example due to dehydration, can suppress the effectiveness of the sense of taste. This dryness can also be a common side effect of a number of medications (for example antidepressants, or antihistamines) and also of a number of diseases (such as diabetes).

There are specific types of taste cells that are stimulated by each of the five taste groups – sweet, sour, salt, bitter, and umami. This last taste has been known to the Japanese for a long time but has only recently been recognised in Europe and the US, where we used to think there were only four taste groups; it's the taste of protein (think of bacon for example). Many books and articles have diagrams that show maps of the human tongue with distinct areas that respond to each of these five taste groups, but now it is thought that these maps are very over-simplified. Taste sensation can be localised on the tongue but sensitivity to all tastes is distributed across the whole tongue, and indeed across the other regions of the mouth where there are taste buds, but certainly some areas are more responsive to certain tastes than to others.

The sense of taste drives the appetite and protects us from poisons, so it steers us towards the right food groups and away from the wrong ones. We need carbohydrates, which is why we like the taste of sugar so much, and we are attracted to salty tasting foods because we must have salt in our diet. We also have a need for protein, and amino acids are the building blocks for proteins, so the taste quality umami, which is the meaty, savoury taste, drives our appetite for amino acids. Bacon is a classic food that stimulates the umami receptors because it is a rich source of amino acids. Monosodium Glutamate (MSG) does the same, which is why so many manufacturers use it as an additive in processed foods – it makes us want to eat them. Bitter and sour tastes cause aversive, avoidance reactions because most poisons are bitter, and food that has gone bad turns sour.

Between 75% and 90% of what we think of as 'taste' is actually 'flavour', which is a combination of taste, smell, texture and temperature sensations. With the sense of smell completely blocked, for example, the sense of taste becomes remarkably ineffective (have you ever tried to enjoy eating a meal when you are completely congested with influenza?). As infants increase their experience of life they also come to associate visual and hearing information with taste memories, so that strong expectations and associations are already unconsciously operating for even quite young children. We can check this out for ourselves. With our noses held to block smell information, something that looks like cheese but tastes like a doughnut would be an unpleasant taste surprise, and produce an aversive response like gagging and spitting, even if we actually liked the taste of doughnuts. Equally, if we held our noses and closed our eyes and heard the sound of a cork popping from a bottle and then the sound of liquid being poured, all familiar indicators that a glass of wine was on its way to us, but then we drank

and tasted strong black coffee, we would have an aversive taste response even if we loved strong black coffee.

So why does the sense of taste go wrong?

- Advancing age.
- Dehydration.
- Certain medications that cause excessive dryness in the mouth.
- Certain illnesses.
- Impairment or malfunctioning of other senses, including smell, touch, vision and hearing.
- Associations made with previous unpleasant experiences that can result in extensive taste aversions.
- Lack of use.

Taste and children with deafblindness

So, there are obviously reasons why other sensory impairments might interfere with the effective working of the sense of taste. Nerve damage, especially to the fifth cranial nerve is also likely to cause under-functioning of the sense of taste. Every individual's response to taste is very unique, and seems to result from a combination of experiential factors and genetic makeup. In the population of children with deaf-blindness there is almost the same wide variability of taste preferences that are encountered in the rest of the population. The exception is the significant number of children with deafblindness who are reported to need very strong tasting flavors, things like sugar, ketchup, chili sauce, and salt, added to their meals before they will eat them. This may reflect the impact of limited sensation coming in through the other senses of touch, temperature, smell, and vision rather than specific damage to the taste sense itself. For children with deafblindness taste and smell preferences might be more strongly linked to the motivation to eat than they are for other children, so it is important that these preferences are ascertained and respected for each child if significant problems with eating and with nutrition are not to result. A severely restricted diet, for example of liquid formula, can result in a very inexperienced and under-used sense of taste, so that tolerance and preferences can become very narrow indeed. In extreme form, aversive responses to taste, texture, and temperature inputs in the mouth can stimulate choking, gagging, and vomiting, so, again, it is important to observe closely and interpret carefully in order to build up a clear picture of the child's preferences and capabilities.

What can we do to help?

- Respect the child's taste preferences as much as possible, while also encouraging exposure to a wider range of taste, texture, and temperature experiences.
- Think about the tastes of the child's current diet and find ways to focus the child's attention on these, maybe by enhancing food and drink flavors in acceptable ways, and by keeping different foods separate rather than blended together.
- For children who are entirely tube fed on formula, seek advice from a feeding therapist for safe ideas to give taste experiences which might one day help to move the child on to oral feeding.
- Work that improves the functioning of other sensory systems (such as smell and touch and vision) can help to ameliorate the impact of under-functioning taste sense, because, in sensory terms, everything is designed to join up and work together.
- If possible, consultation with a feeding therapist and a dietician can be helpful for advice on a wide range of aspects of eating and drinking.

As with any sensory deficit, poor functioning of the sense of taste can be difficult to identify and assess, particularly when it is only a part of a wider pattern of sensory and other impairments.

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Access to literacy: books for all

Stuart Aitken and Paul D. Nisbet discuss the range of issues around accessible formats and how helpful they are for deafblind people.

Over the past 10-15 years many countries have made it easier to produce print materials in adapted formats, without having to seek prior approval from authors or publishers. Each country operates its own checks and balances to ensure compliance. In the UK, for instance, adaptation for individual use is covered by a standard photocopying licence. If the accessible format is to be made available to others who also meet exemption criteria, a special licence has to be applied for, known as a CLA VIP Licence (CLA, 2002). A web-based notification system¹ operates, so that information can be posted to a national database of resources in accessible formats about where to locate print material in an accessible format. Anyone seeking print material in an accessible format can check the website to find out if someone has already done the work and locate the copy, provided copyright exemption criteria are met.

A question of interest to deafblind people, their parents, carers and practitioners is whether the accessible formats available are likely to be useful to the child they work with. Is, for example, the changing nature of deafblindness (Brown & Bates, 2006) reflected in the range of formats available? We begin with the story of one pupil we know.

Helen is in Primary 7 (approx. Year 7 in England, or sixth grade in USA) at her local school. She has arthogryphosis, a physical disability such that she uses an electric wheelchair. She cannot handwrite or hold or manipulate objects. With support, she can type on a keyboard. She loves to read but is frustrated because she cannot hold a book or turn pages. Helen could access printed books with help from another person, or use a mechanical page-turner². At a cost of £2000 – £3500 (\$4,000-\$7,000) and weighing in at 6.5Kg this solution was considered impractical, especially as she was about to enter secondary school where subject classes would mean someone having to transport both laptop and mechanical page turner between classes.

One solution was to source a digital version of the book that Helen could read on computer and use switches to turn pages. Helen wanted to read Jacqueline Wilson's *The Suitcase Kid* (Wilson, 1993). A search of Revealweb did indeed return copies of *The Suitcase Kid* – in Braille, giant print, various large font sizes, and also Digital Talking Book format. There was no listing for a digital version that would have allowed her to turn the electronic book pages using switches. Had the book been available in switch accessible format she would have had independent control of her own reading.

Readers of *DbI Review* might at this point legitimately ask: What has Helen's story got to do with access to literacy for deafblind people? In response, one could argue that, if Helen had had associated visual and hearing impairment, in addition to her physical difficulty in handling books, she would still not have been able to access her desired book in a suitable format. Those formats that were available might, possibly, have addressed her visual support needs, but they would still not have addressed the literacy support needs that resulted from her physical impairment.

If Helen had been deafblind she would not have been the only one to benefit from switch accessible digital versions of print materials. Brown and Bates (2006), among other authors, have drawn attention to a continuing trend showing the changing nature of deafblindness, citing for example data from the 2003 USA National Deaf-Blind Child Count. That year it listed over seventy causes of deafblindness. Of the 10,000 children on the census, 60% were reported to have physical impairments, 68% having cognitive impairments (National Deaf-Blind Child Count Summary, 2004).

Not all deafblind children who have physical or cognitive impairments will benefit from switch access to print materials at the literacy level required to read and understand *The Suitcase Kid*. For many, the experience of reading will be one of appreciating the overall context that forms part of the routine of bedtime stories. Miles (2005) eloquently relates some of the early experiences a deafblind child might associate with reading: a father's breathing; the vibrations of sound in the mother's chest as she reads; the smell of the paper – are examples of the earliest stages of reading characterised as emergent literacy (Smith, 1989). Miles goes on in her article to describe a number of practical techniques and strategies that can help improve access to literacy during the phase of emergent literacy (Miles, 2005). Many techniques and strategies will depend on developing materials that are highly personalised for an individual child, especially if the child is at the emergent literacy level.

Nonetheless, some children at the level of emergent literacy will benefit not just from individualised materials but may also want to access materials that have been prepared for someone who required a similar adapted format. Deafblind children who do progress to Koenig's basic or functional literacy levels (Koenig, 1992; Venezky, 1990), or who are at the cusp between learning to read and reading to learn (e.g. Chall, 1983), are more likely to want to access print materials in alternative formats. What formats are available to them? Is *The Suitcase Kid* the only book not available in switch accessible format? If not, what others are available?

Returning to *Revealweb* we searched for adapted books in the Oxford Reading Tree series (Oxford University Press), a popular UK scheme for teaching pupils to read. We found a range of series titles available in one or more adapted formats of Braille, giant print, large print, audio for blind or partially sighted people. None in the series was available in a format that would allow a switch

user to access the book independently. In fact, out of the 110,000 plus titles listed in adapted formats, no title was available in switch accessible digital format.

Switch accessible digital format is not the only adaptation likely to be of interest to teachers and parents of deafblind children. Materials offering symbol support using such as Boardmaker (Mayer Johnson Picture Communication Symbols, 1981) represent an increasingly important resource for some deafblind people, not only to support their personal communication but also in support of emergent literacy. Increasing consideration is also being given to the use of sign language support to Deaf children either to accompany text or, in the use of video clips showing signing, as a way of assisting the understanding of phonics at the stage of emergent literacy (Brennan, 2004). None of these adapted formats featured in the database of accessible formats in which print materials were available.

There are many possible reasons for a shortage in the range of adapted formats. A simple explanation could be that, in the UK at least, copyright legislation (OPSI, 2002) permits materials to be adapted, but only if the person has a visual impairment. As hearing impairment is not exempt under the legislation it would be unreasonable, according to the simple explanation, to expect materials to be available in formats accessible to those with a hearing impairment. (Though publishers, if approached directly, may well give their consent.) No doubt this is part of the explanation but it does lead to some paradoxical situations. Copyright law will allow materials to be adapted for a deafblind child. If, however, he or she needs sign language supported materials, the child's visual impairment will allow materials to be adapted for sign language support, but not his or her hearing impairment.

What of switch accessible formats? At this point the simple explanation for not featuring in the range of formats, because exemption criteria do not apply to someone who may need switch accessible materials, is found wanting. For, interestingly, 'visual impairment' as defined by the act (OPSI, 2002), actually covers those who cannot hold a book or turn a page, irrespective of whether the person has a visual impairment. Copyright exemption does allow print materials to be adapted for a switch user like Helen. It's just that none has been produced or, if they have been produced, the person assumed that others would not find them useful and so did not add them to the national database of accessible resources.

Helen's story together with the detailed findings of our investigation into accessible formats (Nisbet & Aitken, 2007) have led us to important conclusions, only two of which we mention here.

The first is a general point. The changing nature of deafblindness means that there is much to be gained from findings in other fields of enquiry. In addition to Miles' recognition of the importance of Deaf education and English as a Second Language to improving access to literacy for deafblind children (Miles, 2005), we

would highlight the relevance of findings from the fields of assistive technology and augmentative and alternative communication.

A second, and more specific point may be of interest to readers. If we are to add switch accessibility as an adapted format, how would we describe or define 'switch accessible' format? Both those adapting materials into that format, as well as the people who might then access materials so adapted, will benefit from a shared understanding. At the level of emergent literacy (Chall, 1983), switch accessibility might mean a Talking Book produced in MS PowerPoint, with switch activation confined to an onscreen equivalent of 'turning the page'. At the level of functional literacy (Koenig, 1992) switch accessibility might require full control (search, next page, previous page, and so on) accessed by a single switch. Our current work is addressing these and other areas.

Finally, readers might be interested to know what happened with Helen.

Confident that she was covered by copyright exemption, and being unable to find an accessible version, we scanned the book into computer and created digital versions in MS Word, MS Reader and Adobe PDF formats. We chose these formats, in preference to Daisy for example, because:

- they offer the viewing, navigation, search and study tools that Helen required;
- MS Word was already installed on school computers and Helen's laptop. MS Reader and Adobe Reader are both free;
- MS Word and PDF are inclusive: Helen, staff and other pupils were familiar with these formats and programs;
- MS Word and PDF formats are interactive, allowing creation of digital worksheets and assessments;
- scanning and OCR software can generate MS Word and PDF files directly.

Helen and her staff evaluated the books in the three formats, Word, Reader and PDF. She chose MS Reader as the format most accessible and suitable for her for this book.

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Twelve lessons from the development and operation of an australian accommodation support system for deafblind adults

trish Wetton CEO, Foresight Foundation for the Deafblind, and Mike Steer from the Royal Institute for Deaf & Blind Children, and the University of Newcastle, NSW give us an introduction to the Foresight principles

An Australian with sensory and multiple disabilities is a full citizen with the rights and responsibilities accorded all adult Australians, and is entitled to dignity and respect. The Foresight Foundation located at North Rocks in suburban Sydney was founded 30 years ago by parents of children who were deafblind to provide quality accommodation support services and facilitate training and employment for adults who were both deaf and blind with additional disabilities; and to enhance and enrich their lives. In 2008, Foresight manages eight independent group homes, with 35 full-time, part-time and casual staff providing support to 32 adults with sensory and additional disabilities.

Foresight Foundation staff firmly believe that each resident is a unique and important individual. The agency's Board, staff, the residents, their families and advocates do all in their power to foster a service model that is based on mutual respect. Staff members are trained by the agency to adopt a person-centred

approach to all aspects of its Accommodation Support Program. The agency's objectives are as follows:

- To promote, encourage, foster and develop the care, accommodation, communication and training of adults who are deafblind with additional disabilities.
- To assist residents to interact with others in the community, to protect their rights and treat them with dignity and respect as valued members of the community.
- To assist residents to lead satisfying lives and as far as possible become self-determining.
- To consolidate world knowledge and encourage sponsorship for research.
- To become a model of best practice in the provision of services for adults who are deafblind with additional disabilities.

In its 30 years successful experience at developing and managing a reasonably large accommodation and support system for deafblind adults, Forsight Foundation's management, staff and residents have learned that the following areas are highly important to the success of the agency:

Sound principles

Lesson 1 Services need to be based on sound human service policy principles

Forsight Foundation has developed and implemented policies and procedures including a Code of Conduct, and a Code of Ethics entitled Meeting Individual Needs and Mutual Respect for Others. The ecology of each group is a high priority for Forsight Foundation. Nurturing relationships between residents and also between staff, families and Advocates and residents is regarded as highly important by Forsight Foundation management.

Attempts are constantly made to have each Forsight Foundation group home a welcoming, safe and happy home and workplace. All staff members focus on each resident's needs. The goal is to provide a person-centred service.

Communication training in augmentative and alternative methods of communication include finger-spelling, Makaton and Compic. These are provided to meet individual communication needs.

Assessment

Lesson 2 Residents with sensory and multiple disabilities need to be correctly needs-assessed.

Assessments at Forsight Foundation take into account the centrality of sensory and multiple disabilities to the individual resident, and include consideration of the whole person. Assessments require input from the resident with a disability or an advocate, and from family members and carers. The importance of identifying the range of impairments, the way they combine and the resultant effect cannot be over-emphasised. Early identification and complete assessment leads to effective program development and enhances the probability of providing positive outcomes.

Practical Assessments are conducted in each resident's own group home. Residents are more confident in surroundings and with people they are familiar with. A range of medical and other Assessments are conducted for the Lifestyle & Environment Review, the Developmental Disability Health Unit Care Plan and the Forsight Foundation Care Plans.

Community presence

Lesson 3 Australians with sensory and multiple disabilities have a right to live and spend their time in the community, and not in facilities that deny their access to fellow citizens.

Towards this goal, Forsight Foundation constantly seeks alternatives to such long-stay programs as nursing homes and institutions. The location of a support service is highly important as this can affect opportunities for involvement in ordinary, everyday community life. Residential support services need to be located within easy reach of such community facilities as shopping centres, post offices, community health centres, recreational facilities etc. Proximity to public transport is also highly important. In planning and delivering accommodation support services, equal weight should be given to day activity provision and access to community services.

Residents are able to access their local shopping centre with one-to-one support for personal shopping and personal care appointments. Additional one-to-one support is available through the Group Home Support Centre at North Rocks. Forsight Foundation obtains donations each year to provide support and transport for residents to attend Blind Bowls, Blind Cricket, Riding for the Disabled, RAPS and Hand Over Hand recreational activities in the community. The agency believes that when group homes (including gardens) are well

maintained, residents are accepted by their neighbours and welcomed into the local community. Forsight Foundation welcomes local Service Clubs to participate in special events with residents.

Relationships

Lesson 4 Living in the community is not enough. Relationships in daily life with non-disabled people need as much as possible to be fostered

Forsight Foundation seeks advocates to provide support to residents who do not have family members or friends to assist them to make informed decisions and choices about their lives. Links with Corporate partners allow relationships to be formed between volunteers and residents. Working bees, including group home garden and room makeovers involve community donors-in-kind and residents working side by side on a project.

Professional photographers have become mentors to blind residents, training them to take digital photographs to expand their perception of the world using their senses of touch, sound and smell. New opportunities for building new relationships are continually being sought.

Choices

Lesson 5 A person with a sensory and multiple disabilities has rights of citizenship in the service development process to make views known and have account taken of those views

Residents attend regular meetings where they receive assistance to communicate their views about their group home. They have a representative on the Forsight Foundation Homes' Committee which gives them access to the Board. Under guidance from the CEO, a unique communication link with each resident has been developed to enable all residents to make their views known and be listened to at any time.

Communication

Lesson 6 Opportunities for communication with other people is of primary importance in the development of relationships, since this enables choice and decision-making as well as participation in community life.

Individual Plans include goals for increasing communication skills. Vision Australia, Deafblind Services NSW, Guide Dogs Association of NSW/ACT and the Deaf Society assist the Forsight Foundation to provide opportunities for residents to communicate with other people in their group home and in the community.

Staff receive training in offering choices to residents, just knowing when to hold back to encourage independence is important to ensure that each resident is given the time he or she requires to make choices about being independent and doing things for him or herself. The agency provides weekly Dance Therapy sessions to residents. Positive outcomes from this project include enhanced communication between residents, enjoyment and documented changes in challenging behaviour.

Families, friends and Advocates play an important role in the lives of deafblind residents. Home visits are anticipated eagerly. These highly important links are nurtured by staff.

Home

Lesson 7 Wherever possible, remaining in the family home with support from the agency should be considered a viable option for a person with a sensory and multiple disabilities.

New enquiries for accommodation support programs are referred to the Department of Ageing, Disability and Home Care Vacancy Management Committee. The Department provides Case Management and Assessment options to identify level of support needs to ensure that all viable options are considered. In-home support services are discussed with stakeholders at Individual Planning meetings.

Forsight Foundation believes that all residents where possible, should go home to their families during Christmas and Easter breaks. Regular home visits are encouraged throughout the year.

Educational/Developmental programs

Lesson 8 There must be a consistent and coherent approach to educational and developmental programming across residential, educational, recreational and vocational or occupational services.

Forsight Foundation requires a comprehensive Transition Plan, Funding Agreement and Health Care Plan that clearly identify the unique current and

future needs of each resident seeking to access the service. Adult learning programs and supported employment services are facilitated by the agency and transport to services is provided.

Forsight Foundation staff training includes obtaining Government Certificate IV in Disability Studies and both external and in house training. Competent staff can provide learning opportunities to residents across all programs.

Specialist supports

Lesson 9 These are essential as part of the agency's comprehensive service provision.

An experienced member of the Forsight Foundation management team attends all appointments at the Developmental Disability Health Unit (DDHU) at Royal Rehabilitation Hospital or attends appointments with any treating Specialist with each resident. This practice ensures continuity and accurate information is provided confidentially. A comprehensive Care Plan is developed by the DDHU and regularly reviewed. A team of specialists is involved in the implementation of each Care Plan. In addition, Forsight Foundation Treatment Plans are developed for all hospital stays and Specialist treatments to record all information.

Clinics are conducted regularly by Westmead Dental Hospital, Dysphagia Clinic, Clinically and Macquarie University Audiology Clinic for all residents at Forsight Foundation Group Home Support Centre at North Rocks. Clinicians are always pleased to examine residents who are relaxed in their familiar surroundings. Staff are kept informed of all specialist support arrangements through the Trans-disciplinary team confidential approach using group home computers.

Comprehensive services

Lesson 10 Providing comprehensive supports on an individual resident basis requires a planned approach with emphasis on periods of transition between phases, for example, that which occurs on leaving school for adulthood.

All new admissions require an individual planning approach. The Department of Ageing, Disability and Home Care (DADHC) Vacancy Management Committee oversees all placements. A comprehensive DADHC proposal for funding is based on Assessment outcomes and budgetary guidelines.

Residents entering the Forsight Foundation from School would receive the same process as do adults who transfer from another adult service, such as an Aged Care Nursing Home, or a DADHC large residential or group home.

The location of family and friends of deafblind residents is taken into account to ensure that relationships can be easily maintained. Day programs and supported employment services, including transport needs are identified.

Changing needs

Lesson 11 Program development must take into account the changing needs that arise from; improvements or deterioration of an individual's condition; on-going developmental opportunities, different life stages; and choices made by the individual resident.

The changing needs of deafblind residents are monitored by the Forsight Foundation management and staff in collaboration with other services, families, Advocates and Guardians. A pro-active approach is used to ensure that early symptoms or deterioration of a resident's are picked up. The 'Preventive activities over the Life Cycle' system provides a guide for screening for age related illnesses. Screening is firstly identified in the Individual Plan and then included in the DDHU Care Plan.

An accommodation retirement program operates at some group homes for residents who do not attend day programs or supported employment services full-time.

Lesson 12 Individuals with sensory and multiple disabilities must have support services provided by staff who are well trained, experienced and who are provided with in-service training and supervision.

Forsight Foundation is aware that due to the scattered nature of its eight group homes all staff do not work under 'direct' supervision but 'general' supervision only. To address this isolation and the solo shifts worked at most group homes, Forsight Foundation implements a strict recruitment and induction process to ensure that all staff have the skills required to work with four or five residents alone before being rostered to work at a group home.

Deafblind residents rely heavily on staff to be able to understand them so that they can convey their needs to management. A high level of trust exists between the different levels of staffing. Each staff member receives in-house training in the Life Cycle Model to equip them to become skilled managers at work and in their own life situations. This management training provides staff with the ability to manage critical incidents as they arise and to report them. An Action Planning approach identifies each situation and records actions needed to complete

various tasks with a regular evaluation. Every critical incident reported to management is monitored closely until resolved.

The Forsight Foundation trans-disciplinary confidential approach to group home care, using computers with email access in each group home has been developed so that all staff can work as one team. In-house training in documentation and legal responsibility, medication management, epilepsy management, deafblind communication skills, fire evacuation and use of equipment and complaints reporting and handling are continually offered to all staff. Quarterly General Staff meeting/training sessions are attended by both Forsight Foundation and Agency staff.

Forsight Foundation provides VitalCall direct telephone support at each group home. Individual VitalCall medallions are provided to residents as required. 24/7 advocacy is provided to residents and staff by the CEO and the ASM. A CEO Payroll Memorandum containing valuable information about resident care, group home management and staffing matters is sent out each fortnight with payslips to all staff including Agency staff.

The authors acknowledge the assistance of Sense residential service guidelines in the development of this article.

Country News

Canada

CDBRA and Grupo Brasil

Stan Munroe, CDBRA, travelled to Brazil in November 2007 as part of the continuing relationship between CDBRA and Grupo Brasil that was first established in 2003.

Stan was invited to attend the II International Forum on Deafblindness and Multiple Impairment / IV National Meeting of Families and Specialised Professionals / VI National Meeting of Deafblind Individuals in the city of Aracaju, Sergipe – Brazil, 12-16 November, 2007.

His participation included a presentation at the Panel Session on health and educational worldwide outlook about prevention, diagnosis, attendance and services for persons with multiple impairment and deafblindness and a Round

Table discussion on Studies in Brazil and Canada about the late effects of Congenital Rubella.

Following this Conference, Stan, on invitation of, and accompanied by representatives of Grupo Brasil, Shirley Rodrigues Maia and Laura Monteiro Ancilotto, travelled and lectured in several locations in the Northeast of Brazil. The locations were Fortaleza (Ceara State), Teresina (Piaui State) and Timon (Maranhao State). Stan made presentations on Congenital Rubella Syndrome with special reference to later health effects and prevention and, with the assistance of his wife Carol Munroe, the Canadian Concept of Intervention. Shirley took the opportunity to outline the services of Grupo Brasil to a location of the country where services for deafblind persons are in their very infancy. The presentations that were made during Brasil's Deafblind Awareness Week.

Deafblind Ontario – a new name!

DeafBlind Ontario Services (www.deafblindontario.com) is a not-for-profit organization that creates safe and comfortable environments that enable deafblind individuals throughout the province to live more independently. DeafBlind Ontario Services currently supports deafblind adults with community-based housing, trained intervention support, independent living skills, work experience and social programs.

New developments

After 18 years of enabling adults who are deafblind to live more independently, the organization formerly known as Independent Living Residences for the Deafblind in Ontario, has launched a new name, new logo, and new holiday gift drive to help increase public awareness around this complex disability.

“As the province's largest not-for-profit organization providing housing and 24/7 support services to deafblind adults, DeafBlind Ontario Services has been creating supported-living solutions for almost two decades,” explains Roxanna Spruyt-Rocks, Executive Director of DeafBlind Ontario Services. “More support is needed however, to ensure all deafblind adults have access to the support they require.”

The new logo symbolically represents a house that shelters the ability to see and hear. The new identity coincides with the organization's plans to further enhance its services offered to deafblind adults — including adding another home to its collection of residences located throughout Ontario and developing innovative outreach programs to help deafblind individuals live more independently.

Conference brings out true spirit of intervenors

“I am motivated and energized to be a better Intervenor.” Just ten words from one participant, but they speak volumes about the success of the Deafblind Coalition of Ontario’s recent Intervenor training symposium, which was held at the Deerhurst Resort in Huntsville, Ontario, February 20-23, 2008.

With a focus on Intervenor and the vital role that they play in the lives of people who are deafblind, the conference was designed to address the specific needs of direct service staff working with persons with acquired and congenital deafblindness.

The conference was opened by the Honourable Madeleine Meilleur, Minister of Community and Social Services (Ontario). The three-day event that followed featured a variety of speakers from Canada, the United States and the UK. Renowned for their experience and expertise, these speakers made presentations on a number of topics relevant to the field of dual- sensory loss. In addition, presentations from individuals who are deafblind were extremely well received.

Examples of presentations during the 3-day event included: Consent, Privacy, legislation & Medical Intervention, Holidays for the Deafblind-What a Difference They Make; Understanding Usher Syndrome; Usher Syndrome Type 3: One of the Lucky Ones; Charge Syndrome 101; Deaf and Hearing Cultures: Understanding Each Other; Intervenor: Allies in Empowerment etc.

When conference organizers first sat down to plan this event, they came up with an ambitious theme: The Spirit of Intervenor: Expanding Our Capacity & Profession. It was a theme that clearly struck a chord with participants.

A resounding 94 per cent of the 260 conference delegates said the weekend event met their expectations. “This was my first conference of this kind,” said one attendee. “I found it extremely informative, well-planned, and a great way to meet new people.”

“One of my favourite experiences of life,” declared another enthusiastic attendee. “I thoroughly enjoyed hearing the personal life experiences and subsequent gifts shared by persons with deafblindness,” said one participant.

Feedback from the conference will help organizers plan similar events in the years ahead. Because the 2008 conference truly brought out the spirit of Intervenor, the theme is likely to be an enduring one.

Deaf Blind Coalition of Ontario

Australia

Electronic media access issues

Australia's National Disability Services (NDS) agency reports that a DVD entitled 'Keys to Living Together: Then we were three', that has been produced by the Commonwealth's Department of Family, Housing, Community Services and Indigenous Affairs, is not accessible to new parents who are blind or vision impaired, or Deaf or hearing impaired. Steps are currently being taken to caption the DVD. NDS and the Australian Blindness Forum have asked the Commonwealth Department to take greater steps to audio describe the DVD. In the meantime, access to a Pdf document by that name is via the Commonwealth Department's website at

[http://www.facsia.gov.au/internet/facsinternet.nsf/vIA/families-keys_to_living_together/\\$file/keys_newparents.pdf](http://www.facsia.gov.au/internet/facsinternet.nsf/vIA/families-keys_to_living_together/$file/keys_newparents.pdf).

Deafness Forum Australia, in its January 2008 One in Six Newsletter, includes an update from Media Access Australia about the rates of captioning and audio describing DVDs over the last 16 months – For information on these please go to http://www.deafnessforum.org.au/files/u1/One_in_Six_January_2008.pdf. Media Access Australia also provides an update on the availability of audio-described DVDs online at <http://www.mediaaccess.org.au/audiodescription/default.aspx>.

The Australian Visual Software Distributors Association (AVSDA) has released a DVD accessibility framework document, affirming its commitment to making available access features such as captioning and audio description. The objectives of the framework are to promote the availability of access features for people who are deaf or hearing impaired and people who are blind or vision impaired. AVSDA states that its members are committed to increasing the range of products available with access features. Complaints can be made directly to AVSDA by email to info@avsda.com.au or via the website

<http://www.avsda.com.au/dvdaccess.asp> where the AVSDA members are also listed.

The Minister for Broadband, Communications and the Digital Economy is still considering whether or not the inquiry into media access for people who are Deaf or hearing impaired, blind or vision impaired, announced in October 2007 (ABF Update of October 2007 item 6), will go ahead. The inquiry had planned to consider audio description services as well as captioning and was due to be completed by 30 April 2008.

The other film festival

Entries have been accepted for Australia's only disability film festival, to be held in Melbourne in September 2008. Entries for the 2008 festival could be of any length or genre, but they must be made by, with or about people with disability. All of the selected films will automatically enter the running for the best film prize of A\$5,000, with other prizes yet to be announced. For more information visit <http://www.otherfilmfestival.com/>

Review of accessible public transport standards

A Draft Report on the Review of the Disability Standards for Accessible Public Transport has been available for public comment on the review website <http://www.ddatransportreview.com.au>.

Focus on students with disability

A new DVD, 'The Critical Bridges: Meeting Challenges at Points of Transition in Education by Working Together' has been produced by the NSW Department of Education and Training, the Disability Council of NSW and the TAFE NSW Disability Unit. It aims at assisting teachers, trainers and employers to better understand the needs of students with disability at three critical points of transition: pre-school to school, school to post-school and acquiring a disability in adult years. The first segment features a secondary school girl who is blind. For more information or to order a copy email s.lee.disabilitycouncil@dadhc.nsw.gov.au

Supporting the wellbeing of families and children

The Attorney-General has announced that 75 new services will open across Australia this year to support the wellbeing of families and children. These include 25 Family Relationship Centres, bringing that national network to 65, and 22 new early intervention services to provide individuals and families with the skills, education and counselling needed to prevent family breakdown. For more detail, read the Attorney-General's media release at http://www.attorneygeneral.gov.au/www/ministers/robertmc.nsf/Page/MediaReleases_2008_FirstQuarter_17January2008-Supportingthewellbeingoffamiliesandchildren

Flight closed

The report on the experiences of people with disability in domestic airline travel in Australia, is now available. The report's 112 pages cover the increasing barriers faced by people with disability who want to travel by air. There are 57 proposals that provide reasonable solutions to the physical, social and economic costs of inaccessible travel. For more information, go to the Public Interest Advocacy Centre website at http://www.piac.asn.au/news/media/20071213_fltclsdrp.html

The guide dog conference centre

The new centre has recently been opened by the Association for the Blind of WA. The conference facilities also include the Woodside Guide Dog Discovery Centre. For more information, go to <http://www.guidedogswa.com.au>

National conferences

2008 National Conference of the Round Table on Information Access for People with Print Disabilities will be held in Melbourne on 11 to 14 April, immediately after the Fourth General Assembly of the International Council on English Braille on 6 to 10 April. More information at <http://www.e-bility.com/roundtable/>.
SPEVI Biennial Conference: The 2009 Biennial Conference of the South Pacific Educators in Vision Impairment will be held from on 6-9 January 2009 in Adelaide. The theme of Challenges and Choices will focus on vision impairment, adaptive technology, early intervention and partnerships. For more information, contact Jessica Bosnakis of All Occasions Management at Jessica@aomevents.com.

Ireland

Deafblind Ireland

The steering group of Deafblind Ireland met in Longford on Saturday 12 April. Arrangements for registration as a charity in Ireland are almost complete. The group welcomed two new members, taking the total to 8. We are planning a training event in November in Dublin for professionals working with disabled children. All disabled children are entitled to an assessment of need under new Irish disabilities legislation. The training event will focus on the assessment needs of deafblind children.

Look at the website for more information: www.deafblindireland.org

Romania

Identification of babies and early intervention

Sense International (Romania) continues to monitor the early intervention programme in Bucharest and Oradea, following an action plan established in partnership with the Government, individual hospitals and support centres. The project has established a unique model of multi-disciplinary care involving medical staff, specialists in deafblindness and representatives of the local authorities, with the aim of improving family life for deafblind children and their parents. Achievements made as a result of this work over the past year are:

In Bucharest

- Up to March 2008 an impressive 4,518 new born babies benefited from vision and hearing screening at Panait Sarbu Maternity Unit. Five children have been found with hearing impairments and four have been identified with vision problems. All nine babies have been referred to specialist doctors and have entered the rehabilitation programme, waiting for further testing to see if they are at risk of acquiring further sensory loss;
- Ten children have joined the rehabilitation programme under the supervision of the multi disciplinary team in the Early Intervention Support Centre in Bucharest.

In Oradea

- The programme started in November 2007. Since then 1,738 new born babies have benefited from the screening;
- A total of eleven children have been found with hearing problems and of these, currently two children are benefiting from the early intervention rehabilitation programme in Oradea. We are working with the parents if other children, who are in the process of starting the programme.

The major observations made about the early intervention programme are:

- The provision of very early specialist intervention should focus on supporting parent – child interactions;
- The involvement of parents as active partners at every stage of the intervention process is crucial;

- Studies of young children with visual impairments suggest that the gains attributable to early intervention are greatest in areas specifically affected by visual impairment –for example, orientation and mobility;
- Studies of young children with hearing impairments have emphasised language development and often speech development. Intervention for these children involves both education strategies and provision and use of hearing aids.

A successful application made to The International Women’s Association for a hearing-screening device, allowed us to extend the programme to another maternity unit in Bucharest. After the training session in basic screening organised at the beginning of May, two neonatal doctors will be qualified to screen the hearing of new born babies. Children will then be referred to the Support Centre in Bucharest. The maternity unit will allocate a room, which will be sound proofed, and specially equipped for testing the newborn babies’ hearing and vision. “Ioan Cantacuzino” hospital is the 3rd maternity where Sense International (Romania) has implemented the early intervention programme so far.

Cristiana Salomie

Scotland

Sense Scotland opens TouchBase

As I came into work on the 15th April I was inevitably reflecting on the journey our organisation has made from our humble beginnings in a cloakroom to preparing today for the Royal opening of TouchBase. Our centre is usually an energetic place to work but this morning it was more lively than usual. Staff were bringing in flowers, cleaners were arriving, final lists were being prepared, name badges were being laid out, catering was gathering apace, signs were being put out, technology was being checked, finishing touches to the stage, lighting, seating etc were all being done by different groups of staff.

As the morning went on the police arrived and much to the delight of service users, Sam the police sniffer dog came too. The ever-patient policeman told service user and staff alike “please don’t pat Sam he is trying to work!” Service users were now rehearsing and what a privilege to sit at your desk and hear Murray on his accordion playing The Dark Isle. Yvonne wanted to give a short speech to HRH The Princess Royal and spent the morning checking and refining her words so that they were word perfect. Another service user informed me that he had “googled” HRH and knew where she lived!

Then our guests started arriving and how wonderful they all were. Parents, service users, senior politicians, funders and colleagues from statutory and voluntary organisations all joined us. I felt that people were really there because they cared and I appreciated greatly the time and effort busy people made to join us on our special day. There was a sense that it is everyone's resource, I felt that people have a sense of ownership and that everyone wants it to work. The people who attended enjoyed the day and got a flavour of our work. It was our way of saying thank you for the trust so many people have placed in Sense Scotland. I know guests enjoyed the performance because most of them told me so. The service users had great fun putting it together and the whole experience gives young people confidence, which can lead on to other opportunities. For instance some of the service users are now starting to work in TouchBase and who cares if the mail arrives a bit later? It was a wonderful day and our fantastic centre is now open, lively and energetic with service users at the heart of all that we do.

Gillian Morbey CEO
Sense Scotland

Grupo Brasil hosts the second International Forum

on Multiple Disabilities and Deafblindness and celebrates its 10th Anniversary, November 2007

The Second International Forum on Multiple Disabilities and Deafblindness together with the Fourth National Meeting of Families and Specialized Professionals and the Sixth National Meeting of Deafblind People were successfully held in Aracaju (Sergipe State) Brazil, November 12-16, 2007. The forum and meetings were held at the Central Campus, University Tiradentes in Aracaju.

This five-day event was organized by Ahimsa (Educational Association for the Multi-Handicapped), ABRASC (Brazilian Association of Deafblind People) and ABRAPASCEM (Brazilian Association of Parents and Friends of the Deafblind and Multi-Handicapped), which, together with other facilities in Brazil, comprise Grupo Brasil.

These successful seminars were supported by the Brazilian Secretary of Special Education/Ministry of Education, the National Coordination Centre for the Integration of the Persons with Disabilities, Sense International: Latin America, Perkins School for the Blind and the Embassy of Canada

The general theme of the International Forum was “Holding Hands: Education, Health and Human Rights for Everybody”. Speakers were in attendance from Brazil, Canada, Argentina, Colombia, Ecuador, and the UK. Participation included persons with deafblindness, family members, professionals from the field of deafblindness, and representatives from Government.

Special keynotes and panel presenters known to DbI included Dr. Tony Best (UK), Ximena Serpa (Columbia), Stan Munroe (Canada), Dr. Marta Lucia Tamayo Fernandez (Colombia), Gabriela Rovezzi (Argentina), Shirley Rodrigues Maia (Brazil), Sonia Margarita V. Rodriguez (Ecuador) and Claudia Sofia Indalacio Pereiro (Brazil). The presentations by Sonia Margarita (President of the Federation of Persons in Latin America who are Deafblind and Vice President of WFDB) and Claudia Sofia (President of the Brazilian Association of the Deafblind) gave incredibly uplifting presentations about the successes of their organizations.

Both Sonia’s and Claudia Sofia’s messages gave great inspiration to those in the audience who were deafblind. For example, Sonia said “that we deafblind are human beings that want to fight for our own rights. We will not get pity from anyone so we have to do our own thing”. Claudia Sofia furthermore indicated that “with the benefit of guide/interpreters (or Intervenors) our main goals are to prove to government authorities that we are able, even without our vision and hearing, to do whatever a “normal” hearing and seeing person can”

Grupo Brasil was celebrating their 10th Anniversary as an organization dedicated to developing services and promoting advocacy for the rights of the deafblind and multi-impaired population in Brazil. To date they have been successful in developing services in 19 Brazilian states. Hats off to the wonderful success of Grupo Brasil’s many professionals, family members and volunteers under the leadership of Shirley Rodrigues Maia!

During the closing ceremonies Shirley Rodrigues Maia highlighted their significant progress over the past ten years. Certificates of merits and medals were given to a number of individuals in Brazil who have contributed to Grupo Brasil’s success. Grupo Brasil also awarded Certificates of Merit and medals to Ximena Serpa from Sense International Latin America and Stan Munroe from CDBRA Canada and to Hilton Perkins (given to Gabriela Rovezzi). The medal’s inscription stated: Surdocegueira “Nao há limites para o ser humano” – Deafblindness “There are no limits for the Human Being”.

Stan Munroe
Canadian Deafblind and Rubella Association

The Convention and Civil Society: The Role of Civil Society

Lex Grandia's address to the UN on behalf of the International Disability Alliance

“Let me first congratulate all parties involved with the entry into force of the Convention on the Rights of Persons with disabilities, CRPD. Congratulations to the United Nations and to civil society, especially persons with disabilities. This Convention introduces an enormous paradigm shift. It is a legal way to include all persons with disabilities into society, as full and responsible members of this society.

I am speaking on behalf of the International Disability Alliance, IDA. IDA is a network of international and regional organisations of persons with disabilities. IDA has played a very active role in the formation and the work of the International Disability Caucus, IDC, that was so successful during the process of negotiations around the Convention. IDA is still very active.

Helen Keller, who was deafblind, once wrote:

“Worse than not seeing and not hearing is not to be seen and not to be heard”.

This Convention is making a change:

We will be seen as persons, equal before the law like anybody else, persons with dignity and many qualities.

We will be heard as experts on how to make all areas of society, the environment and information accessible to us. We will be heard as persons giving valuable contributions to society.

We will be seen as persons in the schools and universities, in the workplaces, in society, in cultural life, in politics, in shops and restaurants.

We will be heard as respected members of the family, in the planning, designing and development of goods and services, as citizens, with all the rights and duties citizens have.

We will be seen as persons whose diverse bodies, minds and abilities enrich ourselves and society. We will be heard when we accept or refuse medical interventions.

We will be seen, all of us. the Convention is about all persons with all types of disabilities as a part of human diversity, including women, children, older persons, indigenous peoples and members of cultural minorities with disabilities. Our life stories will be heard and understood.

We will be seen and heard in the media. All this will make society inclusive.

This Convention gives us a legal basis and it will be reflected in laws of all state parties that have ratified or will ratify this Convention. We have legal capacity and may act according to our own decisions.

We, disabled persons of the world, know that the hardest work is ahead of us.

We want all states to ratify without reservations or declarations.

The Convention has to be translated to every language of the world, including every sign language. All ratifying states will interpret and implement the Convention in its national actions plans, legislation and systems.

We, disabled persons of the world, are able and willing to assist states and local authorities in doing that work. Not only are we willing, we also insist on participating in the work. We are the experts on disability issues at a local, national, regional and world level.

Therefore IDA launches the IDA CRPD Forum. The forum consists of all kinds of organisations, working in the disability field, on a local, national, regional and international level. The forum collects expertise on all disability issues, not only from organisations of, but also from organisation working with persons with disabilities. The forum works under the leadership of IDA, which is composed of organisations of persons with disabilities. The forum assists with translations into national, local and regional laws and policies. The forum produces interpretation and implementation material, launches campaigns and follows the developments around the implementation and ratification of the convention all over the world. The forum also assists with the implementation of the Convention in all UN agencies. The forum continues the important work of the International Disability Caucus, but now in the new era after the Convention enters into force. The forum continues the slogan: "Nothing about us without us".

Thank you.

Lex Grandia

National Association of The Deafblind in Bulgaria

The First European Festival of Specific Abilities of Deafblind People

Varna, BULGARIA

01 – 09 September 2008

The First European Festival of Specific Abilities of Deafblind people will consist of the following events

- First European Chess Championship
- First European Amateur Art Festival and Contest

•

First European Championship of General Physical Branches and Track-and-Field Athletics

•

European conference with the topic: “Sports and Culture – means for social integration of the deafblind people.”

•

Constituent assembly of the European Organization of Deafblind Sports and Culture Integration

Every deafblind person can participate in events as she or he wishes (at least one event, up to participation in all 5 events).

PARTICIPANTS: Deafblind persons as participants in competitions:

VENUE: Varna – “The Sea Capital of Bulgaria”.

Varna is a very beautiful and world-famous Black Sea city with sunny beaches, many sights, historical places and attractions.

ACCOMODATION: Boarding-house of “Professor Doctor Ivan Shishmanov” School for children with impaired vision – Varna, very well adapted for persons who are visually impaired.

REGISTRATION AND DEADLINE:

Please check with the NADbB if any places are still available: by e-mailing:

nadbbg@mbox.contact.bg

or by fax: +359 32/ 653 602

Network News

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The Siblings network

From the 22nd – 27th of August “ Listen to me - 4” will be held in Glasgow, Scotland. During this family event the Siblings Network will offer a programme for brothers and sisters of deafblind children who will join their parents to Glasgow. The programme will be decided last minute, as it will be tailored to the brothers and sisters joining, respecting their age and interests. We are planning to have fun! And maybe also to learn something from each other’s experiences. If you would like more information on this great event, you can contact me or Sense Scotland.
We hope to see many families in Glasgow!

Sabine Kersten

Usher Study Group

Marylin Kilsby reports:

Following on from the highly successful Usher Study Group in Perth, Western Australia, we are already making plans for the next Usher Study Group. We will be hosting the Usher section of the Special Interest Day at the Dbl European conference in Senigallia, Italy, in September 2009 and we may hold an USG pre-conference to the same event as well.

I am looking into starting an USG e-group as a way of remaining in contact between USG meetings and also keeping up to date with current thinking and research on Usher issues.

Get in touch if you would like to join us.

marylin.kilsby@sense.org.uk

AdbN

Acquired Deafblindness Network

Ges Roulstone

The co-ordinating group of ADBN met in Oslo on the weekend of 19 – 20 April to finalise the programme for the 7th International Seminar, which is scheduled to take place in Bergen, Norway from 8 – 12 October.

This year the Seminar is entitled “Activity, Ability and Participation, Acquired Deafblindness in all stages of life”. The Seminar will contain 6 plenary sessions and 20 workshops – an increase on previous events.

We look forward to welcoming you to Bergen!

Rubella Network

Nancy O'Donnell

The Rubella Network had its first official meeting at the DBI conference in Perth, Australia, in September! Our session was only about an hour long, but it was just enough time to get the fire going in the group. The room was filled with professionals, parents and consumers with CRS from all over the world. The consensus of the group is that we must not let CRS disappear from global consciousness. Because the incidence of rubella is slowly decreasing or even being eliminated in some parts of the world (thanks to better immunization policies), there is a tendency to think that rubella no longer needs to be addressed. But as we say in the U.S., rubella may be eliminated, but adults with CRS are alive and thriving. Late onset health issues are still a concern and we need to do a better job of figuring out the long term impact of CRS. Our work continues!

At the network meeting, we handed out a short survey to try and get a better idea of immunization policies, numbers of people with CRS worldwide, information

and resources that are available, and how the network can be most helpful. We will compile those results and post them on our webpage

http://www.deafblindinternational.org/standard/network_rubella.html

We received a heartfelt request from Africa for support of national immunization programs throughout the continent. This is a country with many needs and few resources. As a group, we need to take a look at what we can do to help.

There were 3 presentations on rubella at the conference, including the very exciting report by Trees van Nunen and Anneke Schoenmaker of the Netherlands who reported medical and psychological data of approximately 65 adults with CRS born before 1985. Joff McGill of the UK addressed MMR/autism debate. His full presentation, and the latest on rubella and CRS will be available on our webpage.

If anyone would like to add their name to a list of people interested in CRS, please contact me at hkncnod@aol.com

Communication Network

November 8th 2007 was a special day for the members of the Dbl network group on communication. On this day, the students of the first Master Course received their diplomas.

This Master Course is provided entirely by the members of the network group under the auspices of the University of Groningen. For the members of the network group the realisation of the Master Course has been a wish for many years. The Master Course not only provides the opportunity to share knowledge, but also to further scientifically underpin the work that has been done by the members of the network group.

In the mean time the second Master Course is in full swing and the third, that will start in September, is in preparation.

Another important event for the network group is the conference 'Co-Creating Communication with Persons with Congenital Deafblindness' that will take place from October 8th till October 11th in Leeds. The conference is organized by Sense UK in cooperation with the Dbl-network group. The programme and further information about this conference can be found through conference2008@sense.org.uk.

Besides the activities for the Master Course and the conference in Leeds two other topics are on the programme in the coming period. The first is the intention to organize a seminar round the subject 'Deafblindness and Autism' in early 2009. This subject has emerged from a number of workshops in Perth. It is clear

that this subject requires further deepening. The network group wants to set the ball rolling with the seminar in early 2009.

A second topic the network group is studying can be described as 'Construction of Language'. At the moment the possibilities to organize a Paris conference on this subject in 2010 are being explored.

And... last but not least: by now booklet 3 in the series 'Communication and congenital deafblindness' is finished and available at viataalshop@viataal.nl. In the course of 2008 booklet 4 will also become available. During a course, preceding the European Conference in Italy in 2009, all booklets will be presented, including the manner in which they can be used for staff training activities.

Ton Visser

Network Group on Communication

Employment Network

During the past two years I have felt like being a kind of research worker in the field of employment for disabled people. I have become a person who wants to see what is happening with the system, officials, and with people around who are involved with your work in one way or another. I have also attended to many seminars, meetings and discussions around the topic of employment.

Last year I had a job where I got regular pay from a special project. It gave me an opportunity to build up my work from different "slices" – schools, newspapers, Parliamentary, with projects in the deafblind organization and with students, aids and technology! The main aim of the special project was also to help each individual to get his or her feet in the door of work, to see if it works in both sides. My experience was that I had a great opportunity to do a very meaningful job using my skills and education with the people I met and worked with. The thing I was able to offer was my point of view arising from my special needs, professional status and my ability to offer advice and information. This might sound too simple to be considered as work, but after all there are many quarters where all that information is something that is needed. In fact, important information! It can be a significant part of training or education for students, an important information for MPs and important information for someone who wants to improve new aids and technology.

During my work I met a manufacturer with whom I discussed the possibility of an aid that had not before been thought of as an aid for Deafblind people. The aid is an expensive one but I had time to use and test it, free of cost, with two students who will become sign language instructors this spring. I also tested the technology with interpreters. The experience was great compared with anything available before. The needs of deafblind people are very special and deafblind

are most definitely people who are the first to thirst for any progress in their daily life. And I think deafblindness is surely something that offers an endless field of challenges for development.

Last summer I attended a day trip by bus. A group of twenty active business women had arranged the trip. They had sent me an invitation to join them as a member of our city council. I had an opportunity to learn which kind of business each of them have. During the trip we visited some towns where we heard about new ideas from other women, visited an art museum, had a lunch and coffee. I had a sign language instructor with me. I also had an opportunity to tell the ladies about myself, my needs and how to do things. The feedback I got was that there are many different ways to do things, but someone without any information has no idea of anything like that. After the trip I found I had got lots of new friends who send me emails, invite me to join their events, share their ideas and networking. I also have now seen their work and products, too. They have a lot of energy and enthusiasm for things they do.

With students, projects, MPs etc, it is similar. They need different point of views and feedback. When meeting them I always feel I have something they need.

Just great – I'd say!

However, at the end of last year the project was over. To be able to continue it should have needed some significant changes – mainly in respect of the different money policy from the different people who employ me. As my work was like a cake with many slices, there was not a simple solution to who pay my fees so that it provided a living wage.

During my project I gave a monthly report of my day-by-day work and plans to my supervisor.

For example, I do not find it meaningful to have a no job at all, which is not realistic for me. Recently, for example, I received a letter from Employment Office offering me a job as a school assistant. Although I have the education for that, I know I cannot work in a busy classroom where pupils need the kind of help that someone with good hearing and sight can offer. But I also know I can do many things very effectively and that there are many area, too, where my disability is more a strength than a weakness.

My problem is simple: I have not found an employer who requires what I can offer in the workplace and is willing to offer a salary for it. A colleague kept on reminding me that my work is something that only I can do. This is a good reason to remember how individual we are with our knowledge and skills – and that includes deafblind people. The problems we still face are problems associated with the system around us.

It is up to deafblind people themselves to fight for a better future. Who else does this for us?

Let's stay in touch in the employment matters. You can contact me seija.troyano@dnainternet.net for a while. I still have some problems to start an egroup but, I am working on it and will let you know about it as soon as possible.

Seija Troyano

Co-Creating Communication with Persons with Congenital Deafblindness

Theory and Practice

Wednesday 8th - Saturday 11th October 2008

The Royal Armouries Museum, Leeds, UK

The Programme

The conference will address four themes

8 October 2008 – Dialogicality – Professor Ivana Markova

9 October 2008 – Joint Attention – Professor Peter Hobson

10 October 2008 – Gestures and Mimetics – Dr Susan Duncan

11 October 2008 – Language – Dr Kari-Anne Selvik MA

We are really excited about the Conference as it will be attended by delegates from all over the world.

We look forward to seeing you in Leeds!

Only a few places left!

[http://www.sense.org.uk/professionals/
co-creating+communication+conference](http://www.sense.org.uk/professionals/co-creating+communication+conference)

For further information please contact

conference2008@sense.org.uk

Using books with deafblind children at the CESSA educational centre for deafblind children in Larnay, France

Brigitte Lastere and Ghyslaine Gimene, who are educators, have been working on a programme to encourage deafblind students to enjoy stories!

Having fun with books!

Usually, books are used by adults in a teaching situation. When children use books, they physically manipulate them to produce visual and sensory sensations, using them in their own individual way. Books also have other functions to encourage the imagination through dreaming and discussion. So we decided to develop an activity which employed both these functions to engage the children.

Our aim, in this activity, was to help children to mobilize their cognitive abilities: their attention, memory, language and reasoning. And we also wanted to encourage them to play, because the notion of play is difficult for deafblind children, and playing is very important in every child's development.

What did we do?

First of all, we have created a regular consistent time and place to do this work. The group of children arrives and they sit on chairs in a semicircle group. The physical positioning of the group can encourage joint attention and their attention towards the others through visual or/and tactile contact between children. Then we begin. We ask children to remember the story we have seen the week before. This is designed to stimulate their memory. We ask children to repeat our questions about the story to be sure they have properly understood.

Time to respond

Children often need time to respond and they need to absorb the information about what is being asked of them and integrate it before coming up with the answer. We create a setting that avoids anxiety for the child that is contributing. After this reminder of the story, we present a new picture of the story to each child. We question them all about what they saw in the picture: who is in? What the characters do? Where? What they say? The questions are important for us to be sure that children have looked at and understood the picture.

We do this to increase joint attention and with repetition of the situation children can memorize pictures and the story.

Mime

After that, we change our space. We move to another room where we mime scenes of the story. The mime is important because it transforms thoughts into action and gives a reality to what is imagined. The acting of the story helps children to create mental pictures of the situation. There is, in this room, a decor similar to that in the picture. This is designed to help the children to mime the story.

In addition we solicit their imagination and initiatives about the story.

The mime also can help children to understand a picture, to integrate a given situation and emotions expressed. As it is not reality, but acting, they can feel some distance from the emotional state of the story.

Co-activity is important for communication

But the children, with sensory impairments, still have difficulty in communicating. So, adults help them to communicate, to stimulate their initiatives, to support their gestures and movements. As always, co-activity is very important at this time. We have noted an interesting fact. With the mime, children change their place, their role, function. At any moment in a story, they can play an adult, and another time, they play a baby or a student. They have to pay attention to others people and their functions and roles. In this way children learn to understand why adults have certain reactions in this situation and, with support, can extend their experiences of the world.

Drawing the story and making it personal

After the story mime, we move back to the first room. Then, we ask each child to colour the story's pictures. The drawings allow the children to integrate the story in another way by allowing them to create the pictures that make up the entire story. We finish by writing a sentence to summarize the picture, using pictograms or another format according to each child's particular preference and understanding. In this way the children have their own book of the story, with their drawings and written traces of the story included.

Making books fun!

So in this activity, we try to lead the children towards the pleasure of books. We stimulate their cognitive functions, their imagination through mime and play, and encourage communicative initiatives. We believe it also helps them to understand the world.

The Foyer Group up-date

This is just a brief update on developments from the Foyer Group established at the Perth Conference ...from Sian Tesni Roberts

Firstly, I would like to convey my heartfelt condolences to the friends and family of Mike Collins. At the same time as we mourn his death we can also celebrate all he has left through his vision and his dedication to work in developing services

to people who are Deafblind in many countries throughout the world. He was deeply concerned about training and the continued development of services, particularly in countries of the South. In our meeting in Perth at the founding of the Foyer Group, he was particularly interested in how international and local organizations could work together in developing a coherent structure of funding and training.

Akhil Paul gave the group a kick to communication, by providing up to date information on the ratification of the Convention on the Rights of Persons with Disabilities, informing everyone that India and Gabon (Africa) ratified on 1 October the Convention on the Rights of Persons with Disabilities, bringing the number of ratifications to seven (in October 2007). The information sent was interesting and informative. For updated information on signatures and ratifications of the Convention, see <http://www.un.org/esa/socdev/enable> Since then, some communication has taken place. Let's hope that this gets us all going again. If you have any stories, ideas or any other news about educational development, health issues, advocacy, policy developments, work and employment or technological advances to exchange, please contact Sian Tesni from CBM who will add your name to the list of contributors and share your information with the group – sian.t.roberts@btinternet.com

“Meaning Making”

The third booklet of “Communication and congenital deafblindness” is ready!

This booklet is a co-production of writers from Denmark, Finland, France, Norway, Sweden and the Netherlands and is edited by Jacques Souriau, Inger Rødbroe and Marleen Janssen.

What is “Meaning Making” about?

“Meaning Making” is the third out of four booklets on Congenital Deafblindness and Communication, which are written to inspire families and professionals communicating with deafblind children and adults. The way human beings understand the world is an essential issue for seeing/hearing partners of congenital deafblind persons. Because of their dual sensory loss, deafblind persons experience the world first and foremost bodily, which challenges seeing/hearing partners when they try to take the perspective of their deafblind partner, when experiencing the world together, and when they communicate about shared experiences.

What does it contain?

The first chapter addresses how gestures emerge from bodily emotional experiences in the world. The experiences that leave traces in the body and the mind of a deafblind person, often appear as bodily gestures referring to significant aspects of an event.

The second chapter focuses on narratives. The dynamic narrative form is essential for meaning making in all human beings. In this chapter we will address how partners of deafblind persons can use this knowledge in their intervention strategies.

In the third chapter two different but supplementary theories are described, clarifying the processes of meaning making. Katherine Nelson's model on Mental Event Representation and a model from cognitive semiotics are described as supplementary tools. The fourth chapter addresses negotiations, which is the pragmatic phenomenon happening in dialogues between partners, when meaning is co-created and shared.

The last chapter addresses the exposure to cultural language in the case of deafblindness. The specific challenges we meet in tactile communication, when we are trying to introduce linguistic elements, are addressed theoretically and practically.

DVD and its use

There is a DVD enclosed, together with guidelines for watching the video material. It illustrates the essential concepts from this booklet.

Additional titles in this series

Congenital Deafblindness and the Core Principles of Intervention

Contact and Social Interaction

The final booklet, Transition to the Cultural Language, is due out next year

To order a copy of this new booklet or any of the others please turn to the website of Viataal:

viataalshop@viataal.nl

These booklets are the result of an international project executed by The Danish Knowledge Centre on Congenital Deafblindness (VCDBF) (Denmark), Viataal (the Netherlands), NUD (Denmark).

This was made possible by financial support of these centres mentioned and by Revalidatiefonds (the Netherlands) and three Danish funds: Det Obelske familiefond, Oticon Fonden and Det kommunale Momsfond.

Education for all children with Visual Impairment (EFA-VI)

Larry Campbell, President of ICEVI, describes the “Education for All” initiative which seeks equality of opportunity for every child with vision impairment, including those who are deafblind or have additional needs.

For much of its 56 year history the International Council on Education of People with Visual Impairment (ICEVI) focused most of its attention on the exchange of information on “best practice” to improve the quality of education for those children already in school. In 2002, ICEVI engaged in a strategic planning effort that resulted in greater focus on the needs of the 4.4 million children in the developing world who are without access to education.

Three years of serious planning followed and in July, 2006 ICEVI, in partnership with the World Blind Union (WBU), launched the Global Campaign on Education for All Children with Visual Impairment (EFA-VI).

The goal of the EFA-VI Global Campaign is simple and straightforward; to provide educational equity to every child with a visual impairment no matter where s/he lives in this world. How we measure ourselves against that goal is equally straightforward: 1. Have enrollment rates increased? 2. Have drop-out rates decreased?, 3. Are the children receiving the support services they need? and 4. Are children performing on par with their sighted classmates?

The goal of the EFA-VI Global Campaign is to reach ALL children with a visual impairment including those with additional disabilities including deafblindness. However, ICEVI is acutely aware that “the road to hell is paved with good intentions” and that without specific strategies and the collaboration of our colleagues at Dbl children with deafblindness are likely to remain marginalized. For this reason ICEVI is now in discussions with Dbl on how we can work together more closely to assure that the goal of “education equity for every child” includes children with deafblindness.

At this point I can almost hear the questions rumbling around in your head. What makes ICEVI and WBU think that this goal is achievable when for so long the vast majority of children in the developing world have been denied access to education?

That is certainly a fair question. While this campaign carries with it no “gold plated guarantees” we feel that today there are a number of important factors working in our favor. Let me illustrate with four examples:

1. While the EFA-VI Global Campaign is led by ICEVI, it is a program that belongs to the entire community. Today 11 international non-government organizations along with UNICEF, UNESCO and The World Bank are actively involved. For the first time ever the international community is planning and working together on a mutually developed program with a shared common goal.
2. The campaign is being carried out within the framework of the global EFA campaign of UNICEF, UNESCO and The World Bank and therefore is working directly with governments that have developed a national EFA plan.
3. The blind community through its international organization, the World Blind Union, has been fully involved from the outset in the planning, and now, the execution of the campaign.
4. Today the Convention on the Rights of Persons with Disabilities has been ratified and is a powerful tool in our hands to pressure governments to meet their legal obligations to provide an education for every child.

While the road ahead will surely have its twists and turns, initial results show promise. In less than 2 years national plans have been developed and activated in 6 countries with several more scheduled to come online in within the next 6 to 12 months. Our Phase I (2006-2010) goal of reaching at least 14 countries seems achievable. We believe the momentum and success of Phase I efforts will bring meaning to that old expression “nothing succeeds like success”.

It is our intention to regularly update members of Dbl on the EFA-VI Global Campaign, and more importantly, to actively engage Dbl and its members in helping us to assure that the campaign reaches ALL children including those with deafblindness.

Dbl signs a Memorandum of Understanding

with the World Federation of the Deafblind

The Presidents of Dbl and WFDB met at the EDBU General Assembly in Zagreb, Croatia on 26 April to sign a historic memorandum of understanding between their two organisations.

The agreement recognises that, “although we are two separate organisations with two distinct identities, by the strength of our common endeavours we achieve more than we achieve alone”.

The agreement commits the two organisations to:

- Actively share information on a regular basis and submit annual reports to each others Councils
- Actively spread knowledge and information on each others organisations and promote understanding of their work

- Ensure the Presidents of the two organisations communicate with each other on a regular basis to forge closer working relationships and mutual understanding
- Work collaboratively on campaigning issues and policy development
- Create links to each others websites
- Offer each other standing agenda items at each others Council meetings
- Co-ordinate respective events to avoid clashes in the calendar
- Offer standing invitation to each others Presidents to attend their conferences and events.

Speaking at the signing ceremony both Lex and William praised the work of their separate organisations and looked forward to a mutually beneficial partnership.

Ges Roulstone

Secretariat and Management News

Dear readers,

I hope you enjoyed this copy of the magazine. Dbl is keen to interact with its members, engage through various joint activities and stay vibrant in your regions, cities and organisations. It draws its strength and dynamism from your valuable association and contributions.

Change is on its way

This is the last time that I will be signing off from this page as your Secretary. Dbl has received very professional and competitive bids to run the new Secretariat and take up the role as your Secretary. By the time you are reading this copy, the new Secretariat would have been announced. Thank you very much for all the support that you have given me and my colleagues, Parag and Shiv at the Secretariat. Our relationship with Dbl has been an extremely satisfying one and will remain as a pleasant memory. Not in this role, but we look forward to our continued association with Dbl in future. We also hope that you will continue to extend your support and encouragement to our colleagues at the new Secretariat.

Mancom and Council in Glasgow

I am very happy to share with you some updates from the Dbl Management Committee and Council meetings were held respectively on 22 February and 23-24 February, at Glasgow, Scotland.

Following the adoption of the new Dbl strategy at Australia, last September, we have now made significant progress in taking forward the implementing process. A plan for its implementation is now discussed and approved by the Council members. Dbl is currently focussing on 4 priority strategic areas: Information, Advocacy, Networks and Membership. Group leaders have been identified and groups are being formed for each of these areas. Your participation is extremely vital to this process.

Dbl Council is also keen to ensure that the groups responsible to implement the plans receive adequate development and monitoring support. Upon their advice, a new member of the ManCom will be taking up this responsibility. Whilst each of the groups will look at generating income to make their activities sustainable, Dbl is also committed to support these initiatives through limited funds and other available resources.

Next Management Committee Meeting

The next meeting of Dbl Management Committee and Council will be held from 15 -17 September, in Wurzburg, Germany

For more news and details on the meetings you may contact the Secretariat.

European Conference

Information for Dbl European Conference to be held in Italy in September 2009 is included in your copy. More details about the conference can be found in the Dbl website. The local hosts are taking all efforts to make this an enjoyable experience for you. And the Scientific committee members are putting together a programme that promises to be interesting and inspiring. Please register for the conference now!

Dbl continues to depend on the kind support of its members and we remain extremely grateful to all members for their ongoing contribution to the organisation. We very much hope that you will be able to make a similar contribution this year and if you were able to increase this slightly we will be happy to send you a revised invoice. As ever this would make an enormous difference for Dbl.

Secretariat has initiated the process for membership renewals by sending invoice to all its members. The members are encouraged to renew their membership. Individual members can now only pay for a four year period.

Members, please note that the credit card payment facility continues to be used by a majority of our members. Please visit our website to renew your

membership. You can fill the renewal form at http://www.deafblindinternational.org/standard/c_membership.asp and choose suitable option to make your payment. In case you wish to pay by bank transfer you need to quote your Dbl Membership Number.

Mini Corporate Membership

Dbl is very pleased to announce a new band of Corporate Membership from the current year. Mini Corporate membership is available at a reduced fee of 100 to 250 Euros annually to organisations working in developing countries (as defined by the World Bank <http://go.worldbank.org/K2CKM78CC0>). It will be extremely helpful if you could share this information to your contacts as widely as possible, and encourage them to become Dbl members and avail all benefits.

If you know of any organisation that may be interested to join Dbl as a corporate member, please pass on their details to the Secretariat now!

If you have any queries regarding the status of your membership, please do not hesitate to contact the Secretariat.

We hope that you received your copy of the previous issue of Dbl Review (issue # 40). If you have not received your copy, please contact the Secretariat.

We are also keen to update the information we have about you and your organisation, so kindly make sure you fill the online renewal form. If you find any difficulty in making an online payment, please get in touch with the Secretariat, right away.

If you have any queries regarding your current membership or would like to complete the membership form via email, please contact Sumitra Mishra/ Parag Namdeo at: secretariat@deafblindinternational.org or post your query at: Dbl Secretariat, Post Box No: 9601, Janakpuri, New Delhi – 110058, India.

Sumitra Mishra
Dbl Secretary

Dbl is a vital network for all involved in the field of deafblindness. In order to best serve our members, it is crucial that we raise sufficient funds through fees to finance our basic activities. With this in mind, there is a Corporate as well as an Individual membership form for you to fill in. Please encourage as many people as possible to join.

Non-Voting Members consist of individuals, national networks and non-subscribing Corporates. Non-voting members can contribute to the decision making process of Dbl through either a corporate member or an international network. Non-voting members will receive a copy of Dbl Review and other relevant Dbl information.

Non-voting membership costs d30 a year or a discounted d100 for four years. Voting Members are the representatives of corporate members who have paid their subscription fees, and the representatives of recognised Dbl networks.

There are now three tiers of Corporate Membership:

Large Corporates:

Annual Fees between euros 3,000 and euros 5,000

Small Corporates:

Annual Fees between euros 300 and euros 1,500

Mini Corporates

Annual Fees between euros 100 and euros 250

Corporate Members can be nominated to sit on the Council.

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