



Inclusion for a lifetime of opportunities

Apresentação Oral

Workshops

Talleres

2505 Early Intervention of children with Deaf Blind: Bangladesh Experience

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Dr. Shamim Ferdous

Deaf blindness is a very rare disability causing extreme developmental disadvantage. It affects all areas of development, including the formation of very early parent-child relationships, communication, cognition, motor and perceptual development and social and emotional development. These effects begin from birth, jeopardizing both the child's personal development and their situation within their family. Early intervention has been recognized as a means of ameliorating the developmental constraints associated with deaf blindness. Deaf blind are very easily misassessed; there is a need to look beyond the child's overt behavior, and to search for incongruities in development. An understanding of the developmental implications of deaf blindness, and how it manifests in children's behavior, is essential to this process. Knowledge of specialist teaching approaches, also, is vital for those providing intervention. Therefore, developmental consequences of deaf blindness indicate a need for early intervention which involves families, a need for specialist intervention and a need for co-coordinated services. Deaf blind children are fragile learners, whose development can easily be harmed by unskilled teaching. Due to lack of proper understanding of the complex nature of this dual sensory impairments and limited expertise in the area, these children have remained invisible with regards to public policy and specialized services and excluded from the disabilities movement in Bangladesh. The Government of Bangladesh and NGOs, have done very little to address the needs for this population which will not be small in number. The present paper will briefly discuss the situation of the services developed in Bangladesh and the outcome of the service provided by trained interveners, in conjunction with other forms of support, an appropriate model for the delivery of early intervention for children with dual sensory impairments with a focus in programming on assessment and training in the use of vision and audition as well as development of other senses.

2590 A Síndrome CHARGE em questão e as Estratégias utilizadas por crianças portadoras dessa síndrome na comunicação
Pesquisa Científica e Pôster

Dr. Ursula Horsch, Andrea Scheele

Esta apresentação visa exibir os resultados alcançados em uma pesquisa de doutoramento, cujo objetivo era investigar a comunicação de crianças portadoras da Síndrome CHARGE com seus pais. Serão apresentadas fotos e vídeos para facilitar a compreensão da microanálise que foi produzida durante a pesquisa já citada. **Introdução e objetivos:** As informações que serão apresentadas fazem parte de uma tese de doutorado intitulada “A comunicação entre crianças surdocegas e seus pais” (2006-2010), a qual é baseada em um projeto denominado “O desenvolvimento dialógico de infantes” produzido pela Prof^a. Dr^a. Ursula Horsch, projeto que visa observar crianças portadoras ou não de deficiências nos seus primeiros dezoito meses de vida por meio do uso de vídeos. Em seguida, uma descrição detalhada do sistema dialógico e do seu desenvolvimento ao longo dos primeiros 1.5 anos será apresentada, além disso, conclusões que apontem a importância de introduzir educação, o mais cedo possível, também estarão presentes. **Metodologia:** As interações dos pais com seus filhos portadores de surdocegueira, que tenham até seis anos de idade, são gravadas mensalmente durante um ano. Em seguida, as informações presentes nos primeiros quatro minutos de cada vídeo são analisadas por meio do software de computador Interact/Mangold. Após essa etapa, análises quantitativas e qualitativas são realizadas através da utilização do programa SAS. **Resultados:** Os resultados são referentes a quatorze pares de pais com filhos portadores da Síndrome CHARGE, dos vinte e cinco pares, cujos filhos são portadores de surdocegueira, além de também levarem em consideração mais de duzentos vídeos gravados durante a pesquisa. A análise quantitativa revelou a presença de estratégias utilizadas por crianças portadoras da Síndrome CHARGE e salientou a importância do contato visual e corporal, em contraste com elementos linguísticos, como a comunicação afetiva específica utilizada pelos pais na interação com seus filhos (Motherese/Fatherese), em outras palavras, pode-se confirmar a existência de dietas sensoriais que apresentam estratégias sensoriais individuais ou de combinações individuais de diferentes modos de comunicação. **Conclusão:** Geralmente, as iniciativas dialógicas e as estratégias individuais de crianças portadoras da Síndrome CHARGE não podem ser identificadas facilmente por uma pessoa que não seja portadora dessa síndrome e que, portanto, não seja capaz de perceber o mundo da mesma forma. Com base no conceito do homem e a confiança nas competências da criança portadora da Síndrome CHARGE, parceiros comunicacionais podem aperfeiçoar o reconhecimento e a compreensão de iniciativas e de estratégias individuais. **Objetivos:** Informar as pessoas a respeito das competências dialógicas e das estratégias individuais utilizadas pela criança, de forma consciente, de modo a contribuir para que elas sejam capazes de mudar a forma como concebem a sua prática; Mostrar as pessoas que por trás do conceito de diálogo, existe um conceito ligado ao homem, o qual estimula a interação e a confiança.

2591 I don't follow you because I trust in you Early dialogues of a congenital deafblind girl (Waardenburg Syndrome) with Cochlea Implant and her interventioner

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Andrea Scheele , Dr. Ursula Horsch

The session is about a congenital deafblind girl with Waardenburg Syndrome. She is three years old and has a Cochlea Implant. In the shown sequences she interacts with her early interventioner. Video sequences are shown and cut into pieces of content. They are analysed in the plenum. Trust is outlined as a basic element of the dialogue between two partners.

Background and aims: The content which will be presented is an extract of data of the doctoral thesis "early dialogues between deafblind children and their parents" (2006-2010), which is based on the project "dialogic development of infants" by Prof. Dr. Ursula Horsch where infants with and without disabilities are observed through the first 18 months of life by the use of video tapes. Next to a sophisticated description of the dialogic structure and its development through the first 1.5 years, conclusions referring tangible impulses for early education shall be drawn. **Method:** Parents and their deafblind children up to the age of six are monthly video taped in their natural setting for one year during an aimless interaction. The first four minutes of the data are analysed with the computer software Interact/Mangold. Afterwards quantitative and qualitative analyses are made. **Key results:** The results refer to one pair of the 25 participants and more than 200 videos of the study: A three year old congenitally deafblind girl and her early interventioner in an individual tutoring situation. It is shown that the girl provides a lot of multi-plane turn-opening offers which are very sensitive answered by the early interventioner. **Main conclusions:** Altogether, following the child and being empathetic as strategies for successful early intervention are described and outlined via video examples. **Objectives:** We'd like the audience to experience the dialogue competencies of the child very conscientiously to get another view on their own work again; We'd like the audience to become apparent that "following" is a very good strategy in working together with the child; We'd like to show the audience quite plainly that behind the concept of following there is an idea of man which is about relationship and trust and that trusting can i.e. also mean that the child does not follow the adult because it knows that the relationship is strong enough.

2698 Speech Therapy Functional Evaluation. Evaluate to increase the opportunities.

Research Scientific and Evidence-Based / Communication and Language

Oral presentation

Nora Beatriz Sinopoli

This research obey the fact of having a scientific knowledge to evaluate the congenital children and young adults considering their functional levels on communication development as part of the Speech Therapy work. For that we developed a scientific research frame in a quantitative, cross over, descriptive methodology, based in data base analysis of the Fatima institution at Buenos Aires, Argentina. The main goal was to estimate the functional percentage of the test (I.E.F.F.) proposed by the author for congenital deafblind children. The impact that came by loosing the senses, even if they are measure independently one as functional hearing and communication, shows main results, confirming this relation it is important to be careful when you will evaluate, taking in account the environment, the material selection according with the residual senses of the particular child, the time that require and to central the observation on the behavior communication of the child. According with the research hypothesis deafblind children have profiles or patrons in the following dimensions: functional hearing, receptive communication, expressive communication and functional cognition that can be characterize in a quantitative manner? We were able to show that there are relationship between hearing and communication (receptive and expressive) and also get information of how complex are the mechanisms that are working in the functional cognitive ones. The individual percentages in each area, in each dimension, clear shows the functional heterogeneous on that population. That let us observe that even same deafblindness etiologies, have similar function ways, that will show with graphics in the selected cases. That is the fundamental value of this research that is the fabulous answers diversity of a deafblind child or another one. That let us see them as a functional integrity and be conciseness that one child is able to have different functional levels in each area. That will give us the knowledge of the real needs of this population and orientate the professionals that attend them. And as a conclusion to create a “functional evaluation” that let us orientate and plan the treatment offering multiple opportunities in the development and the inclusion. It is necessary to be able to find behaviors that do not let see the “objective measure” and the true potential of each child. The people think that the human been is integral and singular, for that the evaluation should not “label” them. Evaluate is known to do, to work on the needs of each child/young and their family to facilitate the development and achieve the maximum potential and capacities.

2704 Reduction of Stress in Children who are Deafblind

Research Scientific and Evidence-Based
Oral presentation

Catherine B. Nelson, Robin G Greenfield, Holly A. Hyte, Jason Perry Shaffer, Kristen Paul

Individuals who experience long-term stress are at risk for developing physical and psychological disorders (Lee, Ogle, & Sapolsky, 2002; Shonkoff & Phillips, 2000). Unfortunately, for a variety of reasons, children who are deafblind are particularly vulnerable to experiencing long-term stress. The children have a limited ability to perceive information through the distance senses of vision and hearing and are thus unable to anticipate changes in their environment (R. van Dijk, Nelson, Postma, & J.van Dijk, 2010; Nelson, van Dijk, McDonnell, & Thompson, 2002). Sudden changes in the environment, especially in the absence of resources to adjust to them, evoke hormonal reactions including increased levels of cortisol (Janssen, Schuengel, & Stolk, 2002). In addition, the communicative behaviors of children who are deafblind are often subtle and difficult to interpret and thus, are often missed. The children then intensify their communicative signals and cues to express their frustration and mounting stress as they escalate to self-abusive, challenging, or aggressive behaviors (Janssen, Riksen-Walraven, & van Dijk, 2002). There are mechanisms in place world-wide to train teachers on how to work with children who are deafblind and there are many interventions that are widely used in the hope that they reduce stress and ensuing challenging behaviors of the children (R. van Dijk, et. al., 2010; Janssen, et. al., 2002). However, there is a paucity of evidence-based studies that demonstrate which if any, of the interventions are actually effective in stress reduction. This session will describe a study that evaluated the effectiveness of various individualized strategies for reducing stress levels in children who are deafblind. The study utilized a multiple baseline across activities using sequential withdrawal research methodology to answer the following questions: (a) do individually determined stress regulation strategies reduce behaviors that indicate stress in individuals who are deafblind? (b) does the use of individually determined stress regulation strategies reduce the length of time from onset of behaviors indicating stress until a calm, alert state is achieved? and (c) do individually determined stress regulation strategies reduce levels of cortisol in individuals who are deafblind? Three measures of stress were collected: (a) behaviors indicating stress, (b) length of time until child is in a regulated, calm state, and (c) salivary cortisol which has been demonstrated to be a non-invasive and effective measure of the efficacy of interventions for stress reduction (McCarthy, et al., 2009)

2705 Psychological and developmental characteristics of children with usher syndrom

Research Scientific and Evidence-Based

Oral presentation

Bente Ramsing

Children with Usher syndrome type 1 are often in early childhood facing difficulties integrating the use of hearing, vision and balance. They spend a lot of energy to coordinate and integrate the triple sensory loss and the development of motor activities, social interaction and communication. The children are delayed in motor and language development and they behave in ways that often place them in the risk of other diagnoses as autism or cognitive or psychiatric disabilities. This presentation will go through a Danish survey about early states of Usher Syndrome type 1 and the consequences of the difficulties most of the children face even before the manifest of vision impairment. The survey is made on a group of children with Usher syndrome in Denmark. Preliminary results show that the majority of the children face behavioural, social, mental and language difficulties more often than deaf children in general. Many of the children with Usher syndrome type 1, who have behavioural and mental disorders will benefit of a habilitation program focusing on learning to use their senses in coordination and by giving them time and support during their own process of integrating their senses with their motor activities and their language development. In a few case stories I will show how early intervention for children with Usher syndrome and their parents and professionals can prevent development of social, behavioural and mental difficulties

2706 Differential diagnostics leading to a lifetime of opportunities for a young man with CHARGE

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Anne Maria Schoone, Monique Elisabeth Snelting

At the Diagnostic Centre of Royal Dutch Kentalis we regularly receive questions related to so called 'challenging behaviour'. The question to answer is often what causes the behaviour and how to handle it. Within this workshop, we will illustrate the diagnostic process, results and further treatment of a young man with Deafblindness. We will focus on the importance of differential diagnostics using alternative hypotheses and the value of diagnosis by treatment. The case-study we will present is an 18 years old young man with CHARGE syndrome, who is Deafblind, has intellectual disabilities, has limited communication abilities and shows challenging behaviour. The Diagnostic Team for the Deafblind at Royal Dutch Kentalis was asked to assess if his problems could be explained by the presence of autism. Before starting the assessments, we looked at possible alternative explanations for these behaviours. Based on observations and interviews with caregivers, it became clear that this young man would be difficult to assess, because of the difficulties to engage contact and communication. The diagnostics contained conversations with people involved, file analysis and assessment with the young man himself where possible. Based on the findings, several hypotheses with regard to the causes of behaviour were reviewed. The results of the diagnostics show a new and surprising perspective and a different way in approaching this young man. Following the diagnostics, a translation into daily practice took place. The whole network around the young men is included in the process. The emphasis has shifted to adapting the environmental conditions to his needs. The underlying expectation was that the level of challenging behaviour would decline when the young men would experience lower levels of stress. In our workshop we will illustrate the diagnostic process and the implementation of the recommendations in daily practice. What we want to show is that by working multidisciplinary and using alternative hypotheses, you can create lifetime opportunities for a person with Deafblindness. After our workshop, there is an opportunity to discuss about the importance of differential diagnostics when assessing a person with Deafblindness.

2707 Creating opportunities for a deafblind elderly person who had no chances in his life

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral presentation

Anne Maria Schoone , Monique Elisabeth Snelting

A 71-year old man is living in a residential home for 40 years. He is totally blind and totally deaf since youth and is living with persons who are profoundly intellectual disabled. His environment has not been adapted to the combination of visual and hearing problems. He's a man who seems very calm and passive. He uses a lot of tranquillizers, at the moment he doesn't show externalizing behaviour problems. So, what's the problem? Fortunately, this man has a strongly involved family. They did see a problem: no one seemed to notice what he needs. At the moment, he doesn't show a lot of skills that he did show many years ago. He seems to be surviving in an environment that is not adapted to his needs, instead of living a quality life. For this reason, the family contacted the Diagnostic Team for the Deafblind at Royal Dutch Kentalis. They asked to assess the opportunities of this man, especially in the interaction with the people around him. They asked for suggestions to improve his quality of life. When we arrived at the residential home, we saw a man who was very deprived and didn't take any initiatives at all. During several "hands-on assessments", this man showed us his possibilities to interact with other people and to take initiatives. He even enjoyed doing so! This created great opportunities for his future. In this workshop we will show you the diagnostic process, including the practical advices we gave. After our workshop, we want to discuss with you how to localize persons like this man, whose specific ask for help has not been recognized. By reaching these people, opportunities can be created to include them in the society. In this way it is possible to improve their quality of life.

2708 Scaffolding Heroes!

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral presentation

Odette Haubrich

This presentation is based on the thesis Odette Haubrich wrote for her Master study “communication with congenitally deafblind persons” at Groningen University in 2010. The research was carried out at the Kentalis Rafaël school for deafblind children and young adults in the Netherlands. The main goal of this research has been to find out what processes in education of deafblind children can contribute to establish a feeling of competence and even heroism. In other words, how can we help our deafblind students feel like strong and confident heroes. In the presentation it will be explained why this is important; Although developmental processes are universal, the conditions under which deafblind children grow and develop are very different. The barriers set by a dual sensory impairment that limit the possibilities of developing a strong, positive and resilient “self” can be extremely high. That is why in this study it has been investigated how teachers can deal with these complications within the educational approach of their school. This research has been set up from dialogical theory, a theory that has become more and more important in recent years in the field of deafblind education. Dialogical theory is based on the idea that every human being has the innate capacity to grow and develop from relationships with others. It is in line with the theory from developmental psychologist Lev Vygotsky, who’s ‘Zone of proximal development’ explains how a child can grow when it is stimulated and helped by the people surrounding it. His developmental theory and dialogical theory have formed the base for this study that was named “Scaffolding Heroes”. The research has shown that a strong stable relationship based on mutual trust between student and teacher is the most important prerequisite for a student to develop a positive self image, and to be able to feel like a hero. It has been a qualitative research that although it has not revealed any absolute truth, it has connected the psychological aspects of learning to the cognitive aspects of learning, which is something that is still sometimes too easily forgotten in education. In this presentation the research and it’s underlying theories will be presented in an interactive manner and video recordings will be used to illustrate the findings.

2713 Inclusion through Transition- A Reality

Education/Rehabilitation Innovative Approaches for Children and Adults
Oral presentation

Leela Agnes

In India most of the deafblind children are identified or referred to professional at later age (10years to15 years) for training. Usual procedure of starting with basic education/skill training and ending up with vocational training may not be relevant for this late comers since it may require many years to complete the process for rehabilitation. Considering the late admission and also their age ,Holy Cross service society have designed an innovative transitional program for adolescent deafblind focusing individual based knowledgeable training either through life orient education (non formal)or through academic support (formal education)to meet the end need of vocational. In this programme the period for intervention is fixed and it involves family members in the planning as well as in the intervention process. This programme aims to help the young deafblind person and their parents or guardians to plan for their future and bring together the professional who have expertise in different areas. Holy Cross Service Society, Trichy is implementing and practicing this type of transitional programme for the past five years and we have seen fruitful and successful result from deafblind. I will be presenting the outcome and the impact of this innovative programme which will prove the way we found the solution to meet the life long needs of adolescent deafblind within shorter duration. I will be sharing this with case studies of deafblind persons who successfully integrated and had opportunities to live happily as an adult in the community after the intervention.

2716 Communication and Beyond

Staff Development Effective Models and Creative Approaches

Oral Presentation

Angela Christine Wills

Where does communication breakdown? Too often the blame is placed with the individual who is deafblind. Support staff report problems with behaviours that are deemed challenging. Eg. Steve has lashed out at support staff a number of times ... Staff are regularly needing to intervene to prevent Steve attacking other clients ... Steve is demanding, always wanting attention ... Steve is jealous if attention is given to other clients ... Senses Foundation undertook a project in 2010 setting up a group home facility for three young men with sensory impairments and intellectual disability, with two of these residents being deafblind. The transitional period raised a number of issues when shortly after moving into his new home, staff reported that Steve had been displaying challenging and aggressive behaviour. Attempts to determine the triggers of these behaviours highlighted barriers with direct communication with Steve. As with any organization, there is a need to evaluate strengths and weaknesses in service provision. Whilst Senses Foundation has excellent and committed staff it was recognized that there was a breakdown in communication between services and between staff. Senses Foundation recognised the need to ensure staff at all levels who were involved in any way with Steve were communicating effectively with each other, as well as with Steve. During the transitional period very little information of Steve's communication skills was passed on by the previous provider – the first in a sequence of barriers to communication. In addition to support staff, up to seven other staff members had been involved from a range of services. Inconsistencies were evident in the way staff, with varied skill levels, were communicating with each other and with Steve - further communication breakdown. Gathering information from all sources was vital to ensure a clear understanding of Steve's communication needs when developing a communication plan to support him in settling into his new home. This project provided valuable learning experiences for Senses Foundation to evaluate and use the experience as the organization moves forward with plans for further individual services for people who are deafblind. This workshop will offer an overview of the learning experiences; tools used and steps taken by Senses Foundation in adopting a more coordinated approach to service delivery. It will also discuss how the organization supported staff with continuing professional development which has led to more effective and appropriate support leading to positive outcomes for our clients who are deafblind.

2717 Deafblindness, Alström Syndrome - early diagnosis and early intervention

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Berit Rannasen , Kerstin Muller , Claes Möller

Hugo is a 5-year-old child with Alström Syndrome (AS). AS is genetic with many organs involved. Severe congenital visual loss with early blindness (14-18 yrs), progressive hearing loss with acquired profound deafness (30-40 yrs), among others cardiomyopathy (heart disorder), obesity, developmental problems, early metabolic syndrome (diabetes, high blood lipids, hypertension). The workshop will be using a bio-psycho-social framework focus on several different aspects of deafblindness. In a 5-year-old boy, the impact of visual and hearing loss on speech, language and communication is vital to analyze. We will further address the strength and weaknesses in social interaction with a special emphasis on play. We will discuss the play with objects, peers and adults and the importance of good environment. In A S special features such as eating habits and diet, is important especially in relation to the many folds of medical problems. How does the prognosis of a serious disorder and possibly early death affect family and personnel? The workshop will be an interaction between the medical profession (Claes Möller) and an expert of children with deafblindness (Berit Rönnåsen). New information about the topic: Early interventions. It is unusual to have such an early diagnose of A.S. Have not been reported before; Interdisciplinary approach considering Alström syndrome presented in a case study; Using the bio- psycho-social framework as a model for future habilitation.

2718 Cognition in Interaction? Assessing Tactile Cognition in Persons with Congenital Deafblindness

Research Scientific and Evidence-Based
Oral Presentation

Hans Erik Fralander, Jude Nicholas

It is a challenge to assess underlying cognitive abilities in persons with congenital deafblindness. Expressions are difficult to interpret and analytical tools related to tactile cognition are missing to a high extent. A Nordic project has been conducted to deal with this. We have come to an insight that the only possible way is to assess cognition in interaction. The method par excellence is video based observations of every day interaction, given that social and physical factors affecting actions are mapped and clarified in interviews with associated persons. It is possible to observe a level of complexity in interplay and to plot changes over time. Using scales, built on experiences of deafblindness and neuropsychological knowledge about cognitive functioning, potential and eventual deviance could be extrapolated. Different prototypical models and scales are under development. We would like to give a brief description of two of them; applications of a checklist on deployment and regulation of working memory during tactual tasks and an analytical procedure to evaluate social cognition in the context of tactile communication, built on recruitment of elements into sharable communicative spaces.

2720 Dancing Dialogue

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Ivana Macokatic

The purpose of this study is to examine the efficiency of two combined “body based“ therapies applied during treatment of a ten year-old girl with cochlear implant, with a goal of reducing stereotypical behaviour, increasing body awareness and improving communication. The relevant therapies are the Vibroacoustic Therapy and Holistic Dance Movement Pedagogy. The vibroacoustic therapy was introduced by a Norwegian musician/researcher, Olav Skille, in 1982. It uses low frequency tones in the range of 30-120 Hz to treat a variety of conditions. It has been proposed to be an effective treatment for individuals with challenging behaviours. Holistic dance and movement pedagogy is a method that contains elements of contact improvisation, authentic movement and bodywork. The concept was created by an Austrian dancer/holistic dance and movement teacher, Sabine Parzer. Both treatments will last for 13 weeks in total and they will be regularly implemented once a week. It will be divided in two sessions. The first session involves dancing, during which the child will learn dance elements such as walking, rolling, lifting, turning and centering. During the dancing activities, the communication included is conducted in a more natural way than in the classroom environment. Every action is followed with gestures and signs, before and after each element happens. The mentioned elements happen in the same order during every session. Child progress will be measured by the Communication Matrix Profile for Parents and Professionals. Duration of the dance session is 30 minutes. The second session is Vibroacoustic Therapy in which the child will receive 10 to 30 minutes of vibrations of 40Hz. The aim is to reduce the stereotypical behaviour. Before and after the session happens, each child will perform the same activity so that the frequency of stereotypical behaviour can be measured. In order to monitor and evaluate the course of each session, every session is videotaped. The results of the two described combined “body based“ therapies will be discussed.

2721 Development late in life

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral presentation

Dorte Lindberg Jensen, Helle Sander Christiansen

“Development is also able to happen quite late in life” (Rødbroe, Souriau, Janssen red.): Communication and Congenital Deafblindness IV, 2009. This sentence inspired us to focus on the pedagogical work and strategies with one of the deafblind residents of our household. Steen is a 58 year old male with congenital deafblindness, Usher Syndrome and special needs. Through his life his behaviour has had obsessive elements which has made it difficult for his surroundings to be in dialog and relation to him. Within the last couple of years Steen’s behaviour has changed, and he had become including towards the staff. We find this change very interesting and would like to focus on this in our workshop. Before the change the staff thought of Steen’s behaviour as negative and obsessive. We decorated our home environment as simple as possible to avoid that Steen became disturbed and destructive. After a few years we decided to give knick-knack a go in our living room and see how Steen would react on this new thing. Steen showed a big interest in this object, he started to build, play and explore this knick-knack in shape of tree wooden bowls. Steen’s team began to buy different types of things. In our work with Steen we used tactile communication and focused to accept and reciprocate his initiatives and we met Steen with patience and tolerance in order to understand his needs and initiatives. Then Steen began to work constructively and creatively. Now Steen has access to many different kind of toys/activity-knick-knack. Today Steen sees possibilities in involving himself in social interactions. Before he often declined help from the staff, but now he enjoys communicating with staff and allows staff to help him in different situations. On the other hand staffs are happy to be active participants in Steen’s life, and to participate in activities with Steen as equal partners. For Christmas Steen got a toolbox, which is the latest stage in his development. He receives help to use the tools in any way he decides. Often he wants help to make different sorts of holes that he can explore. We see a lot of possibilities in developing even further Steen’s creative and innovative skills, because these projects gives him a lot of quality in life as well as we can use our experiences with Steen in our work with the rest of the deafblind people in our household; especially the pedagogical strategies. In our workshop we will focus on the process that led to this change in the relation and social interaction between Steen and staff: 1 - History and background; 2 - The knick-knack; 3 - Our pedagogical approach to Steen’s interest in the knick-knack; 4 - What did the change in relation between Steen and staff mean to Steen’s quality in life; 5 - Further perspectives.

2722 Afters Laura and Helen: The Changing Face of the School-Age Deafblind Population in the USA

Education/Rehabilitation Innovative Approaches for Children and Adults
Oral Presentation

Barbara B Mason, Pamela Ryan

Since the education of Laura Bridgman and Helen Keller, there have been significant changes in the deafblind population in the USA. The impact of the Rubella epidemic beginning in the late 1960's caused a huge shift in the education of students who were deafblind. This trend continued for years, until most of the rubella population aged out and transitioned to adult services. During the past twenty years, there have been other significant changes in the population of students who are deafblind, and these changes have had tremendous impact on the delivery of educational services. This includes an increase in children being born with CHARGE syndrome, CVI and with other etiologies. Along with the changing population of students also came philosophical changes in how and where to best educate these students. This presentation will look at those changes from three different perspectives: 1 - The National Perspective: Using data from the United States Government and Deafblind Projects around the country, we will look at the current population of children and young adults who are deafblind, ages 0 – 22. We will address issues of etiology, sensory loss, age, educational setting, and other physical or medical challenges.. The ongoing discussion of the definition of “deafblindness” and the need for a continuum of services will be addressed. 2 - The State Perspective: We will present a case study of one New England state and look more specifically at some of data reflecting the changes in the population of students who are deafblind and the impact on the delivery of services. This has been especially evident in the change in service delivery to meet the needs of children with significant medical challenges. 3 - Perkins Deafblind Program: We will look at the changes in the population being educated in the Deafblind program at Perkins School for the Blind. and how the educational system has adjusted to meet their needs. The challenge of maintaining a clear and focused mission of who we serve, while adjusting to the overall educational needs of a diverse population of children who are deafblind, will be discussed.

2727 FORMATION OF COLLABORATIVE TEAMS: a path to a responsible school inclusion

Staff Development Effective Models and Creative Approaches

Oral presentation

Marcia Maurilio Souza, Shirley Rodrigues Maia, Sandra Regina Stanziani Higinio Mesquita, Vula Maria Ikonomidis, Dalvanise de Farias Duarte, Lilia Giacomini, Miguel Martins Ólio, Roberta Correa Fernandes

In this paper we present the development of a Cooperation Agreement between Ahimsa – Educational Association for the Multiple Impaired and the Secretary of Education of the City of São Paulo and the results obtained. In this agreement Ahimsa should give a Course of Formation of Collaborative Teams for the inclusion of children and teenagers with deafblindness and multiple sensory disabilities. About 220 professionals from the municipal system of education participated, among them teachers, coordinators, school masters/directors, teachers from resource classrooms and trainees. These professionals belong to eight Centers of Formation and Follow up to Inclusion (CEFAI) and were divided into ten groups according to the CEFAI they belong to, and the trainees were divided into two groups with classes on Saturdays and the others were divided into eight groups with classes at night twice a week. The courses took place from August 2009 to October 2010, and each course had duration of sixty hours of program with the content on deafblindness and multiple disabilities, assessment of students with deafblindness and multiple disabilities, teaching strategies and resources that facilitate and support the inclusion of this population. This training course was designed from the project supported by Perkins International / Lavelle in which the following document was prepared "The inclusion of children and youth with deafblindness and multiple disabilities: a responsible vision." This document lists all the necessary support for students with deafblindness and multiple disabilities are included in regular schools. The results we present were observed through: a course evaluation form, papers presented to complement the hours of the course; visits to schools in which educators work to observe the students served. We can say that a new vision of inclusion is being established in the schools where these professionals and educators work, creating a true "Culture of Inclusion."

2730 Focus on Usher

Program Models Suggestions for Improvement of Service Delivery

Oral Presentation

Chretienne van der Burg

People with Usher Syndrome have a lifetime experience with a decrease of visual capabilities in combination with hard of hearing or deafness from birth. In all stages of life, it has consequences for their activities and participation. As a consequence, people with Usher syndrome repeatedly have to make difficult and thorough decisions and search for new opportunities. Professionals are involved all through their lives: sometimes very closely, sometimes at some distance. This involvement starts at the moment the diagnosis of Usher is set. In our Organization Royal Dutch Kentalis, we evaluated the support to people with Usher by assessing when and how our professionals are involved in the different stages of life: what do they offer and are they easily accessible for people with Usher. Do we have the right resources and support for people with Usher to enable them to develop their best potential? We want to know this because we want to improve our services. The Royal Dutch Kentalis is a national organization in the Netherlands providing diagnostic, care and educational services to people for whom the ability to hear or communicate is not a matter of course. Due to the fusion of three organizations, there are now approximately 85 locations of Kentalis spread over the country. Mostly, people with Usher syndrome visit the location in their region. In such a big organization, it is not easy to arrange that every person with Usher syndrome gets the same amount and quality of resources and support. There is a risk that the quality of support is dependent on the expertise and experiences of the individual professional. Because there was no overall overview of services and support in our organization, we formulated the following research questions: How many individuals with Usher Syndrome do we serve?; Which services and support do we offer in the different phases of life and in different stages of vision loss?; How do we prepare children, young adults and adults to their future and enable them to develop their best potential? In our presentation, we will discuss the results of an inventory of the services and support of individuals with Usher Syndrome delivered by our organization. In a database, this information is systematically registered from records of our clients, and related to age and degree of vision loss. With this survey, we will map what we are doing, so that we can connect knowledge and exchange experiences within our organization. Our aim is to improve the quality of our services and support, and to develop supportive relationships for life between professionals and people with Usher syndrome. The conclusions and results of this research will be available in September 2011.

2732 Improving the use of tactile strategies in everyday interaction and communication with individuals who are congenitally deafblind â A Pilot Study

Research Scientific and Evidence-Based

Oral presentation

Hermelinde Huiskens

In this workshop a recently developed communication intervention, that has been designed to improve interaction and communication between congenital deafblind individuals and their sighted and hearing communication partners, is presented. The communication intervention has been designed to train the communication partners of congenital deafblind individuals to participate in the world of proximity and touch that congenital deafblind individuals use for interaction and communication by means of a training program on using tactile strategies in everyday interaction and communication. The communication intervention has been developed and tested during a pilot study in which two young children with congenital deafblindness and their communication partners were followed for over a year in two different settings: home and school. Communication partners were trained during three phases that were designed for the intervention program. During the first phase of the intervention program communication partners were trained in using tactile sign language in everyday interaction and communication with the children. The second intervention phase focused on improving the communication partners' skills regarding tactile interaction in everyday situations. The third intervention phase focused on the important role narrative based conversations can play in everyday interaction and communication with individuals who are congenitally deafblind and the major role tactile strategies play in these narrative based conversations. Communication partners were trained in creating narrative events during everyday situations in which the tactile impressions for the children were meaningful and motivating. Furthermore, this third intervention phase trained communication partners to create conversations about a narrative event after the actual narrative event had taken/took place. The results of the pilot study show very positive effects of the intervention on communication partners' use of tactile strategies in everyday situations of interaction and communication. During this workshop the intervention program, its different intervention phases and the pilot study and its results will be presented and illustrated by means of video. After the presentation of the results of this pilot study, the audience will be actively involved in a discussion on the implications of these findings for practice and research on communication and language in individuals who are congenitally deafblind.

2733 Usher syndrome - physical and psychological health

Research Scientific and Evidence-Based

Oral presentation

Moa Wahlqvist, Claes Moller

This presentation is part of a larger study on Usher syndrome and physical and psychological health and factors that promote health. The aim is to study physical and psychosocial factors that promote health among persons with Usher syndrome type II and III. Usher syndrome is an inherited condition that impacts both hearing and vision, it can be separated into three different clinical groups that are named I, II and III. To have Usher type II means that the individual have a congenital mild to moderate hearing loss that is quite stable and a normal balance, the vision problems are constituted by Retinitis Pigmentosa (RP) with an onset in the teens and a progressing course during life. Usher type III means that the person have an acquired profound hearing loss with an early onset and RP as in Usher type II, and progressing balance problems. To have a diagnose that has a progressive course from the vision involves great consequences on communication and daily life; this can effect the psychosocial wellbeing in a negative way. Another aspect is the relationship between geno and phenotype, which is the effect of specific mutations on vision, hearing, balance and possibly other organs, not yet known. Two different questionnaires have been used, the National public health survey that covers physical and psychological health among people in Sweden and the Hospital Anxiety and Depression Scale (HADS). The national public health survey contains of approximately 75 questions concerning health, illness and wellbeing, social relations, stress and suicide thoughts/attempts. The HADS is a self-assessment scale that is validated and used for detecting depression and anxiety. These have been answered by 96 persons (45 men and 51 women) with Usher type II and 16 persons (5 men and 11 women) with Usher type III. The results for the Usher population are compared to a normal Swedish reference population. The results and consequences of psychosocial factors such as depression, anxiety, self esteem, thoughts of suicide, within Usher type II and III will be closely discussed at the presentation. All results are preliminary at this stage, but as far as we have analyzed there are differences when it comes to general health, depression, anxiety and thought of suicide and suicide attempts between persons diagnosed with Usher syndrome type II and III and normal Swedish population. This research work contains new research that has not been presented earlier.

2736 Improving interaction and communication. Is it still possible in adulthood?

Research Scientific and Evidence-Based
Oral Presentation

Kitty Bloeming

De Brink, part of Royal Visio, is a residential setting in the Netherlands for persons with intellectual and sensory disabilities. Among the persons who live here, are persons who are congenitally deaf-blind. Most of them did not receive deaf-blind education. Some years ago, two group homes started specifically for adults with deaf-blindness at De Brink. This is called here Project CHANGE. Six participants of Project CHANGE were followed during the first two years of the Project. Video recordings were made, divided in three different time spans. These were analyzed in order to measure effects of Project CHANGE on interaction and communication with the participants. Project CHANGE implied eight major changes for the participants, e.g. a better staff-client ratio, living in smaller groups, together with only persons with deaf-blindness, and intensive use of video analysis in the coaching of the caregivers. The expectation was that taking part in Project CHANGE would improve interaction and communication with persons who are congenitally deaf-blind in adulthood. In the Netherlands, there are many adults with congenital deaf-blindness living in residential settings for persons with an intellectual disability. It is very important that they are approached in a way that is adjusted to their deaf-blindness, but this is not always the case. This easily limits the persons' opportunities to develop interaction and communication. For them, it is important to know if Project CHANGE leads to an improvement of interaction and communication. During this presentation I will give an overview of all the aspects of Project Change. The results will be discussed, illustrated with video examples.

2737 Improving interaction and communication in adulthood. An intervention study.

Research Scientific and Evidence-Based

Oral Presentation

Kitty Bloeming

De Brink, part of Royal Visio, is a residential setting in the Netherlands for persons with intellectual and sensory disabilities. Among the persons who live here, are persons who are congenitally deaf-blind. Since six years, there are two group homes specifically for adults with deaf-blindness at De Brink. Congenital deaf-blindness is a very complex disability, which leads to serious risks for development. A complicating factor for most of the adults at De Brink who are congenitally deaf-blind, is that they did not receive any deaf-blind education in their youth. At De Brink an intervention study was performed at the group homes for persons with deaf-blindness, with the aim of finding out whether it is possible to improve interaction and communication with persons who are congenitally deaf-blind in adulthood. The study is a cooperation with two universities, the university of Groningen (RUG) and the university of Nijmegen (Radboud university). Five adults with congenital deaf-blindness and ten of their communication partners took part in the intervention study. The intervention study followed a multiple baseline design. During the study, the communication partners were recorded on video once a week during 19 to 27 weeks, while interacting with the same person with deaf-blindness, in the same situation during the whole period. After the baseline period, a training program started, consisting of five individual training sessions for each communication partner. In the first three sessions the main focus was on interaction. The method CONTACT, developed by Marleen Janssen, which has proven to be effective in improving interaction with children who are congenitally deaf-blind and adults with intellectual and visual disabilities, was applied. Caregivers were trained on eight core categories of interaction, for example confirmation and affective involvement. Video analysis was an important tool in the coaching. The topics of the fourth and fifth session were Bodily Emotional Traces (BET's) and the narrative approach. Caregivers were trained in recognizing and evoking expressions that are based on a Bodily Emotional Trace. These are thinking expressions loaded with emotion, which refer back to an earlier experience in a bodily way. These expressions are of major importance, because they show us what is important for the deafblind person. During this presentation, I would like to give an overview of the design of the intervention study, the content of the training program, and the preliminary results. Video examples will be used during the presentation to illustrate some of the concepts.

2738 Diurnal salivary cortisol curves in adults who are congenitally deaf-blind

Research Scientific and Evidence-Based

Oral Presentation

Kitty Bloeming

Cortisol is a glucocorticoid hormone that is produced by the adrenal glands. It plays a role in normal states of activity, and during periods of stress. Normally, cortisol levels show a circadian rhythm, with a peak in the early morning hours and with the lowest values around midnight. A temporarily rise in cortisol levels, e.g. in reaction to a challenging situation, supports adaptive functioning. Chronically increased cortisol levels, due to high levels of stress, however, can have negative effects on physical and mental health. Deviancies in the cortisol circadian patterns have been found in different groups, for example in emotionally maltreated children and in foster children. There are numerous reasons to expect that persons with congenital deaf-blindness face stress, and, as a result, have a cortisol curve that differs from that of persons without disabilities. Among the factors that may lead to stress is the lack of well functioning vision and hearing, which may make daily life less predictable and controllable. In a study, performed at Royal Visio, De Brink, the cortisol circadian rhythm of seven adults with congenital deaf-blindness and an intellectual disability was determined, and compared to a control group of healthy subjects. Cortisol was determined by taking saliva samples from the participants. In this presentation the development and consequences of deviancies in the cortisol circadian rhythm will be discussed. The results of the study at De Brink are presented. After the first determination of the cortisol circadian rhythm, it was determined at four subsequent moments. In between, the participants faced major changes in their lives. It will be discussed what the effect is on the cortisol circadian rhythm and how this can be explained.

2739 The Vision-Hearing Project: exploring dual sensory impairment among older Australians

Research Scientific and Evidence-Based

Oral Presentation

Jane Ellis, Julie Schneider

Background: Combined hearing and vision impairment is an increasingly frequent disability due to population aging. The Vision-Hearing project has been developed as a practical extension of Australian research findings from the Blue Mountains Eye Study, a representative population-based cohort of Australians aged 49+ years. The Vision-Hearing project aims to pilot a hearing screening service model and gather data on the effectiveness of this model to inform health policy decisions. The objectives of the study are to: identify the amount of dual impairment among clients attending vision rehabilitation services; to assess the extent of unmet need for hearing services objectively and subjectively among low vision clients; to determine whether the hearing screening model improves access to hearing services and aids; and to determine whether the hearing screening model provides positive benefits to clients in terms of quality of life and hearing handicap questionnaire scores. Methods: Clients attending low vision services at Vision Australia are invited to attend a research interview and free hearing screening test with a research audiologist. Clients who fail the screening test are encouraged to attend hearing services for a complete assessment and will be followed-up approximately 9 months post screening for review. Results: As the study is only in the early stages of implementation, emerging trends from the first 12 months of data collection will be presented. This includes information on the profile of clients participating in the study, including levels of hearing loss and unmet need for hearing services identified. Conclusion: Partnership projects developed collaboratively between researchers and service providers can provide useful insights to inform evidence-based service policies.

2742 Tech Heads: Introducing Young Children Who have Deafblindness to Technology

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Melanie Robartson, Fiona Kemp

It is vital that children who have deafblindness are offered early learning opportunities to help them to reach their full potential, however technologies that provide opportunities for play and active interaction may be overlooked. Frequently the families of and people who work with these children can be overwhelmed by the complexity of the condition or conditions resulting in deafblindness and information they have been given, they can feel at a loss when it comes to what might be termed the child's "play time". While there are technology free methods to employ, technology too, can enrich these children's lives. Technologies can afford children with deafblindness the opportunities to experience, engage, participate and initiate in a world beyond their immediate selves. Both low and high tech options are available for these children and can assist with developing: core learning skills such as shared attention, object permanence and cause/effect motor skills attention to and processing information from the impaired senses integrating information from all the senses individualised communication systems and establishing a foundation for language development This presentation uses an expanded version of a model, borrowed from literature in vision impairment to analyse the child's skills and thereby provide a guideline for the choice of technologies. It explores what features of technology may make them interesting to and engage a young population with deafblindness, sculpting an environment that supports their use of these technologies and a display of practical examples of the popular "favourites".

2747 DETERMINATION OF THE OPINIONS AND EXPECTATIONS OF THE MOTHERS HAVING MULTI-DISABLED CHILDREN RELATED TO THE EDUCATION OF THEIR CHILDREN

Families Supports and Partnerships

Oral presentation

Pinar SAFAK , Omur Gurel , Mualla Ozlem Simsek

The children, who are affected by the disability in Turkey, should first be diagnosed in order to take advantage of a special education organization. However, none of the evaluations serve to evaluate the multi-disabled and deafblind children and place them in an education environment. The standardized conditional tests were not standardized in order to evaluate these children. On the other hand, the modules cannot evaluate the multi-disabled children since they were prepared to evaluate only one of the disability types. The difficulties are faced with in the educational evaluation carried with modules when the disability of the child gets worse and there is a problem in the linguistic skill although the child has only one kind of disability. The child is placed in a public school having the same title with the disability type and providing a special service (School for the Visually Impaired, etc) if the child is affected by only one type of disability and the disability of the child is not at a very high level as a result of these evaluations. The children, who are multi-disabled and deafblind and cannot be placed in the public schools providing special service in Turkey, are directed to the private education and rehabilitation centers. But any education, except individual education for 2 hours in a week, is not given in these centers. The deafblind and multi-disabled children should take full day education when their needs are taken into consideration. Also, the teachers, working in these centers, can have limitations to study with these children since they are trained as the specialist in only one type of disability such as the teachers working in the public schools providing special education. Due to these reasons, it is considered that the sufficient education is not given for the multi-disabled and deafblind children in Turkey and the opinions and expectations of the parents of the multi-disabled and deafblind children, who are the parties of the matter and affected with this problem, should be determined in order to promote this thought. No study can be found related to the opinions and recommendations of the mothers about the special education who have multi-disabled and deafblind children when the national literature is researched. With this purpose, the opinions and expectations of the parents regarding the special education who have multi-disabled and deafblind children who continue special rehabilitation centers will tried to be determined in this study. The qualitative research method will be applied. In the research, the focus group discussion, that is used in the qualitative researches, will be made with 16 mothers having multi-disabled and deafblind children who are given special education in the Special Education and Rehabilitation Centers in Ankara and the semi-structured interviews will be carried out when the focus group discussion is not completed or when the participants will make personal additions during the data collection process. The qualitative data of the research will be analyzed as the descriptive.

2749 A co-ordinated research strategy to explore the impact of deafblindness across the lifespan

Research Scientific and Evidence-Based

Oral Presentation

Dr. Anna McGee

As a result of the anticipated demographic change in the human lifespan, Sense UK has implemented a research strategy that maps the outcomes of deafblindness across the whole developmental journey. There are three projects currently underway within Sense. The Rubella Immunisation Project is developing strategies to engage ethnic minority groups who are particularly vulnerable to rubella infection in the take up of the MMR immunisation so that herd immunity can be achieved to protect children from passing this agent on to pregnant women. The CRS Project has been established to examine the long term health profile of those who were affected by rubella prenatally so that doctors can be alert to the wide range of health difficulties experienced by such people. The BUPA project involves the development of a screening tool for use by care-workers in residential homes for the elderly to identify the early signs of acquired dual sensory loss. Preliminary data from all three projects will be presented. Five new projects have now been launched to alert the worldwide research community to the need for a greater focus on the impact of dual sensory loss. This paper will explore these projects, within the context of the others that are already underway within Sense, to create a renewed understanding of the specific needs of people with dual sensory loss. The projects begin at infancy and end at old age and are designed to contribute to mapping a complete picture of the life experiences of these groups of people so the projects will support deafblind people themselves, their families and other stakeholders in understanding how their full potential can be achieved. The first project is an investigation into the provision of opportunities for parent/infant joint attention in a tactile modality rather than a visual or auditory one. The development of a functional assessment tool to identify the optimal educational environment for individual deafblind children as they enter pre-school or school is the second project in the schedule. The third consists of an investigation of the impact on self-identity of the timing of the diagnosis of Usher and the extent to which the way individuals receive their diagnosis alters their perception of self and/or their intended lifeplan. The fourth project will evaluate the factors that lead to older people with acquired dual sensory loss remaining in the community rather than entering residential care. The final project is an investigation of the ways in which Haptic communication could be used to maintain the engagement of deafblind people with rewarding social activities that define their personal interests. As the researchers working on these projects and others engaged in similar work will need to share their findings with the widest possible audience, Sense has decided to establish the Journal of Dual Sensory Loss, which will include submissions from both UK based and international research groups, to facilitate this aim.

2753 Transition to Independent Living

Program Models Suggestions for Improvement of Service Delivery

Oral Presentation

Timothy S. Hartshorne

Many parents worry about where their child will live when he or she grows up. This presentation reviews the major choices and then illustrates a four step process for making a decision: identify desired life experiences and goals, determine the pattern and intensity of support needs, develop an individualized plan, and monitor progress. These steps will be illustrated by the presenter's personal experience with his son who has CHARGE syndrome. There are three primary options for the future living arrangements for children with CHARGE: live with their parents, live in an institution or group home, live in their own home or apartment. Each arrangement has its own advantages and disadvantages. After reviewing these, the presentation will present a four step process for planning. First, Person Centered Planning is a useful tool for identifying the desired life experiences and goals for the child. It addresses the dreams, fears, and needs of the person, and develops an action plan designed to help the individual have the kind of life that will meet their goals and desired life experiences. Second, the Supports Intensity Scale is a useful measure for identifying the supports needed to sustain the person in their future living arrangement. Third, an individualized plan can be based on the goals established in the Person Centered Plan and the identified support needs, and implementation steps should be identified. Finally, each step of implementation needs monitoring for progress, and such monitoring should be on-going throughout the person's life. This is the process the presenter used in facilitating his son's move into his own home. Any long term arrangement needs careful thought and planning over a period of time.

2754 CHARGE Syndrome: An Overview and Update

Research Scientific and Evidence-Based

Oral Presentation

Timothy S. Hartshorne

Much has been learned about CHARGE syndrome since it was first identified in 1979. Very little was written about CHARGE until 1985 when six articles were published. The first conference and the beginning of the CHARGE Syndrome Foundation were in 1993, a year when nine articles were published. A gene for CHARGE was found in 2004, and the next year 33 articles were published, including a special issue of the American Journal of Medical Genetics devoted to CHARGE. 2010 saw publication of the first book on CHARGE and 25 articles. Clearly knowledge has increased tremendously, and the goal of providing a lifetime of opportunities for people with CHARGE requires a constantly updated understanding of the syndrome. This presentation will provide a detailed introduction to CHARGE syndrome as it is understood today. Understanding of the genetics of CHARGE keeps expanding and will be included, but will be simplified for the presentation. Also discussed will be issues in diagnosis, problems with puberty including hypogonadotropic hypogonadism, adolescent and adult issues, behavior challenges, sensory issues, and issues still in need of research. The variability in the manifestation of CHARGE will be highlighted. It is very difficult to talk about "typical" CHARGE. Some people with CHARGE are extremely delayed while others are college students and professionals. Age of walking has been found to be a marker for how well children with CHARGE do in a number of areas, and this will be discussed. Finally, CHARGE is being recognized as a major cause of congenital deafblindness, and yet not all children with CHARGE are identified as deafblind, raising many issues about education, intervention, transition, and inclusion.

2755 Developing Good Working Practice using a Framework of Seven Principles and Video Analysis with People who have Sensory Impairments and Limited Communication Skills

Staff Development Effective Models and Creative Approaches

Oral Presentation

Anne Telling

To provide high quality services, it is important to support staff to develop the skills and knowledge they need to best support deafblind people. The presenters of this workshop have developed a framework of principles which they have used for many years in their services. The Framework of Principles is combined with the use of video as a non-academic, self-reflective staff development tool to give visual feedback with a framework for discussion to develop staff skills. The presenters introduced their work to colleagues through Sense's National Practitioners Working Group on Communication, resulting in being asked to deliver training on the use of the Framework of Principles and video to develop staff practice. This work inspired 11 Practitioners, 22 staff and 11 people with sensory impairments and limited communication skills to take part in the research project. Description of the Research The main objective was to compare the development of staff skills using a framework of seven key principles developed to support staff to work and interact with deafblind people, where: one group used video to reflect upon their practice, (a method called Practice Supervision) and the control group didn't use video and relied upon their perceived recollections for analysis. The Seven Key Principles that form the Framework: 1. What are the aims of the Activity? 2. How did I tell the deafblind person that the activity had commenced and did they anticipate? 3. How did the person and I interact during the Activity? 4. How I used Sign, Speech, objects of reference, pictures, etc 5. How I used physical guidance, physical prompts and verbal prompts? 6. Had I given the deafblind person time to complete the task? 7. What was my role in the task? Have I done things for the deafblind person that they could do? Why these Seven Key Principles? The development of the principles evolved over a period of many years of experiences working with people with congenital and acquired deafblindness. Although there is no evidence of these principles within any literature on deafblindness, literature supports the focus of these principles as what underpins the development of good working practice when interacting with people with congenital and acquired deafblindness. Methodology Within Sense services, 11 experienced practitioners and 22 staff were involved in the project over a period of eight months. Four Practice Supervisions, observations of interactions between the staff member/communication partner and the deafblind person, were videoed or observed, and then the practice analysed by the staff member and their supporting practitioner using the Framework of the Seven Principles with or without the video for analysis. Research Findings The findings from the pilot study concluded that video was an extremely effective tool enabling the self-reflection process by allowing the staff to see their practice, and use the framework to target key areas for development. Immediate changes in practice were observed, producing more successful interactions, resulting in positive feedback from practitioners and staff. The presentation will include video evidence from the Practice Supervisions showing a demonstration of a tool for staff development and the success it brings!

2756 Young Adults Who Are Deafblind and Advocacy: A Participatory Action Research Study

Research Scientific and Evidence-Based

Oral Presentation

Dr. Susan M. Bruce

Self-advocacy, a component of self-determination, is a set of behaviors that can be applied to protect and promote the civil rights of one person or a group. Test, Fowler, Wood, Brewer, & Eddy (2005) identified four components of self-advocacy: knowledge of self, knowledge of rights, communication skills, and leadership skills. Many high school students graduate without adequate self-advocacy skills (Eckes & Ochoa, 2005). Carr (1994) asserted the following as important to self-advocacy by young adults who are deafblind: recognize their potential to make their own decisions, learn the decision-making process, access to information to support decision-making, and opportunities to practice decision-making. Kirshner (2008) suggested that young adults may increase civic engagement by learning to frame policy proposals and by interacting with policy-makers through joint advocacy efforts with veteran advocates. These principles guided the development of this participatory action research study and its associated advocacy efforts. In June 2009, six young adults who are deafblind traveled to Washington D.C. for a one-week course on leadership and advocacy offered at Gallaudet University. Leaders from the Helen Keller National Center, American Association of the Deafblind, and Texas Tech University briefed the young adults on four legislative issues that impact the quality of life experienced by children and adults who are deafblind. Each young adult selected one or two of the legislative topics as the focus of their advocacy during Congressional visits. The participants further refined their communication, self-determination, and advocacy skills within the classroom setting (where briefing occurred) and in meetings with legislators. In addition, they assumed responsibilities as co-researchers in a participatory action research study that examined their development as change agents. Further, participants in the 2009 advocacy effort became mentors for a new group of young deafblind advocates for the 2010 course. This presentation will orient the session participants to the course offered and to key findings from our research with the consumers. Primary data sources are observations (videotaped), interviews, and journals. Validity of findings are supported by the full transcription of interviews, member checks with the participant/co-researchers who are deafblind, ample citation of interview quotes, and triangulation across data sources. In the post training interviews, the participant/co-researchers who are deafblind indicated the following as being important to effective training in advocacy: access to information about policy issues, knowledgeable mentors who understand deafblindness, and opportunities to practice advocacy skills while interacting with elected officials. Through their interviews and journals, participants shared how their personal stories and personal strengths impacted the advocacy process. Highlights from their continued advocacy efforts will be shared.

2757 Working from the needs, NGO experience

Families Supports and Partnerships

Oral presentation

Vasquez Maria Antonia, Carolina Valeria Magnoli, Roxana Ochoa, Alejandra Fumarco, Adela Irusta de Abramo, Martha Milatich

Since 2001 and forward, our organization had been working on the Río Cuarto, Argentina with double motivation of in one side could answer the real needs of the deafblind and multiple disable people and the other side to be represented in the effective team work in which are professionals and parents. In this scenario, the goal with this presentation is to share the way and to analyze it in the real national and international context that demark the rime and limited and ability the actions and outcomes as a NGO we had planned. The disable person place and their participation possibilities, as the fulfill of his/her rights ha suffer a process on the last 10 years and in Latin American countries in small communities as the one on Río Cuarto, the world policies moved to create a NGO. Doing a fast checking in our city we can find different needs such as achieving scientific researches, positive aspects in health to answer the pathology request and today we can think in a new age group such as the disable adult, the adult that survive the parents and has to leave in a residence. As well as the families those have the same “pathology at their members that request a place to be unit, to share their needs, to create an organization leader by parents.

2759 Keep in touch

Staff Development Effective Models and Creative Approaches

Oral Presentation

Ingrid Korenstra

November 2010 a new group home for 4 male adults with congenital deafblindness was started at Bartiméus, an organization for people with visual impairment in the Netherlands. Within this group, which is the 6th group home for deafblind at a residential facility, 3 adults did not have former experience with a specialized deafblind approach. This created the unique possibility to study the effects of this approach on the interaction and communication of adults with congenital deafblindness. In this presentation we will show the outcomes of a study of these effects which was conducted for the Master Communication and Congenital Deafblindness at the University of Groningen. The focus of the study was to reflect on one of the prerequisites of harmonious interaction: the tactile modality. The results such as presented are the outcomes of the effects on an intervention that aims to foster the use of the tactile modality in the interaction between 3 adults with CDB and their communication partners. The intervention consisted of staff training, using the concepts of dialogicality, dyadic interaction and tactile modality. The effects on the tactile skills of caregivers were measured using video observations and analyses with the involved caregivers. The effects on the tactile skills of the persons with CDB were measured using mapping of the tactile expressions. Our measurements will be further explained in the presentation by actively involving the audience in video-analysis. Finally, we will discuss if there are boundaries for the development of tactile skills in adults with CDB after a certain age and for seeing-hearing partners who support them.

2760 Usher Genetic Lab in Venezuela: strategy design as a molecular indirect identification alternative of heterocygotes for Usher 1 B in families, through analysis of haplotypes

Research Scientific and Evidence-Based / Syndromes

Oral presentation

Tany Fonseca de Pérez, María Luz Neri de Troconis, Elvis Pérez Duque

Nueva Esparta State in Venezuela has reported a high prevalence of Usher 1b (76 : 100.000 people). Since 1999, Socieven (Deafblindness in Venezuela) has identified and supported more than 121 cases of Usher Syndrome (Type's I and II) community based advisory services and rehabilitation. It is developing an alliance with the East University in a project called "Usher Genetic Lab" to study the families that have Usher Syndrome. We hope to study and benefit 770 persons that could be affected based on 70 persons affected by Usher syndrome and 10 members of each family. We hope to become a reference of how to find the Usher population doing the genetic test to confirm the diagnostic. Usher syndrome I B, causes deafblindness through a recessive autosomal carrier (means a person that has the "affected gene, but does not have usher syndrome) ? That means that to have an affect member (means a person that has the "affected gene, but does not have usher syndrome) at the family is defined as a mutation carrier. That means that the mutation will be in some family members and they will be carriers but not suffer the syndrome. If they can be identified, they could get genetic advice regarding the risk of producing a child with Usher syndrome. In this work we analyze the haplotypes, previous ligament analysis as a molecular identification alternative of the carrier families with at least one Usher I B affected member. We designed for that a haplotype made by 5 DNA markers type intra genetic SNP.

2761 Assessment of the communicative potentials of persons with congenital deafblindness

Research Scientific and Evidence-Based

Oral Presentation

Erika Boers

Content An outline of the PhD research 'Congenital deafblindness and Assessment'.
Description The aim of the PhD-research 'Congenital deafblindness and Assessment' is to develop an assessment procedure that can assess the communicative potentials of persons with congenital deafblindness. This session will provide information about the content of the research, and does particularly focus on: (a) the development of a valid and reliable instrument that can be used to assess the quality of interaction and communication between a person who is congenitally deafblind and his communication partner; and (b) the development of a dynamic assessment procedure to assess the communicative potentials of the person with congenital deafblindness.
Purpose Persons with congenital deafblindness often have a severe communicative delay. Considering the fact that communication is the entrance to social-emotional and cognitive development, this has tremendous implications on all aspects of the development of the person who is congenitally deafblind. However, an issue of great concern is how best to assess the communicative possibilities and needs of persons with congenital deafblindness to facilitate their communicative development, learning, and quality of life. We are developing an assessment procedure for assessing the communicative potentials of persons who are congenitally deafblind. The purpose of this session is to present the different components of this study. Specific attention will be paid to a new developed instrument that assesses the quality of interaction and communication between a person with congenital deafblindness and his communication partner, and 'dynamic assessment' for assessing the communicative potentials of persons with congenital deafblindness. Video-examples will be used to illustrate certain aspects of the assessment procedure.
Questions · How can the interactive and communicative skills of a person with congenital deafblindness and of his communication partner best be assessed? · How can dynamic assessment play a role in the assessment of the communicative potentials of persons who are congenitally deafblind?

2762 “Tuning In” - Using video analysis in an early intervention programme for children with deafblindness

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Steve Rose

Description of the presentation: The presentation will give a background of the theory behind the development of the 'Tuning In' early intervention programme. The impact of the programme will be demonstrated with outcome measures and video examples. Main Purpose: 'Tuning In' is a pilot early intervention programme using the principles of Parent-Child Interaction Therapy, video analysis and the co-creating communication model of communication development (Nafstad and Rødbroe, 1999). The impact of deafblindness on the development of communication and the impact that disordered communication development has on the interactive dyad is well documented. In this presentation we will present how parent-child interaction video analysis has been used to reduce communication breakdown and to foster harmonious interactive relationships between parent and child. This innovative project was developed to produce a model of intervention aimed specifically at the needs of deafblind children. Two cohorts have been piloted involving 6 families of deafblind children. The 'Tuning In' programme includes § a baseline assessment, including baseline measures, § a workshop for parents and carers, § a series of home visits, including outcome measures, § a end of programme gathering and evaluation. The workshop session is aimed at increasing parents' knowledge about the impact of the loss of distance senses and identifying strategies to support communication and communication development. Home visits use video analysis of practitioners and parents interacting with children followed by reflection on the interactive episode, using this tool as a mechanism to put the knowledge from the workshop session into practice. At the end of the programme all participants are brought together for a final session, celebrating development and establishing ongoing support relationships between parent's and carers. This presentation will review the outcomes of the initial pilot work, review case studies of the impact of the programme and illustrate the progress made by deafblind children and their parents using video case studies. In addition we will review the recommendations for the future developments of the pilot programme, including possible research threads.

2763 Transition to adulthood in Argentina: An innovation experience leading to an independent life

Program Models Suggestions for Improvement of Service Delivery / Transition to Adult Life

Oral presentation

Paula Rubiolo, Aurea María Souza, Graciela Ferioli

The transition concept began in the middle of the 1980's to consider the services that young adults, who were near completion of their formal education, require as they grow into adult life. We are referring here to the individualized needs for these young adults to ensure their independence within their family, community and social environment. In Latin America each country has a different concept of this transition. For this reason, Perkins International in partnership with ONCE Foundation for Latin America (FOAL), created a group of parents and professionals that came together to produce a document on the issue. The definition that the parents and professionals defined is the one that are being used. In Argentina there are different experiences in the transition process. However it is difficult to have a residential place for the young adults, because in our culture if you do not marry you stay with your parents for ever. The ideal residential place for the young ones will work on autonomy, self-esteem and empowerment of their own lives based on their possibilities. For that reason, it is important that the young adults, together with their families, professionals, community and politicians work together as a collaborative team. . It is necessary to start a progressive process in which the social system creates the links required to solve the independence of deafblind and multiple disabled people when they become adults. For this need a project was created involving INGOs Perkins International, Foal, national organizations Sullai institution and the government

2765 My past, My Present, My Future and the Role of the MSI Education Adviser

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral presentation

Jenny Laura Fletcher Stone, Caroline Potter

Caroline was born Deaf with a significant visual impairment. By the time Caroline was 14 she had become totally Deafblind with some additional motor difficulties. She is part of an incredibly supportive family who were determined that Caroline's disability would not handicap her in achieving her hopes and dreams for the future. This was not an easy task as attitudes towards congenitally Deafblind people can be negative, furthermore educational, social and leisure opportunities in the UK are limited. Like her twin sister, from the age of 16 Caroline was determined that she wanted to leave home and go to college at 18; this is a very natural route for young people to follow in the UK but not always for young Deafblind people. In the workshop Caroline will talk about her past life in the north of England, where she is now (at college in the South West of England) and the journey she took to get there. She will talk about the obstacles she still faces and her hopes for the future. She will discuss the importance of her involvement in her own transition from being a child to becoming any adult, how she expects to be consulted and provided with the opportunity to make informed decisions by knowing the options available to her. Through this workshop she is hoping to inspire Deafblind people, parents and professionals and provide them with an example of good practice that they can apply to their own situations. Caroline volunteers as a play worker with Deafblind children and is aware that not all Deafblind young people communicate using Hand under Hand signing. Through the use of DVD she will demonstrate that young people can represent themselves in the transition process no matter what their preferred mode of communication may be. Jenny will jointly present the workshop giving her view as a professional. She will explain how Caroline has been and continues to be supported by Sense to obtain equality of education; and to have the social and leisure opportunities that are so important to her. Jenny will highlight the importance of training for the educational and social care staff based at the college, both awareness training and training highly specific to Caroline's unique multi sensory needs; this includes training to her peers who are not Deafblind. She will discuss the crucial role of key people such as Intervenors, funders, family and friends and the preparation necessary to ensure a smooth transition. In 2009 Sense produced 'Getting a Result'; a DVD designed for professionals supporting young Deafblind people through the transitional planning process. As part of the Workshop the DVD will be shown to provide the perspective of some of the important people in Caroline's life. Caroline uses hand under hand signing to communicate and she hopes that participants in the workshop will join in by communicating directly with her or through her interpreters to ask questions about her life and her hopes for the future.

2766 Connecting senses with deafblindness project

Program Models Suggestions for Improvement of Service Delivery

Oral presentation

German Guerrero Gutierrez, Diana Carolina Forero Buitrago, Enrique King (guide interpreter)

Access to information and communication are fundamental human rights according to the UN Convention of the rights of disabled people. Based on this, the Technology Information and Communication Ministry together with the Colombian Association of Deafblind People (Surcoe) developed a project called 'Connecting senses with deafblindness'. This initiative, which began in 2007, attempts to promote information and communication access for deafblind and multiple disable people through the use and implementation of technology. The national government, together with public and private organizations in different regions in Colombia, allowed us to start 17 Internet Technology rooms in 16 cities throughout the country. This service offers benefits through the internet for 2900 people to chat, participate in workshops and receive various types of training. These free IT accessible technology services include the use of software 'jaws', screen readers, amplifiers, text scanners, Braille displays, Braille printer and loops. The process includes training personnel in each location (an IT coordinator and other supporters) about deafblindness and multiple disabilities. Together over 300 persons have been trained throughout the country. The program includes an awareness phase through various communication strategies that informs the public about deafblindness and multiple disabilities as well as and promoting the IT rooms.

2767 HOW DO PEOPLE WITH USHER SYNDROME LIVE THEIR LIVES?

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Bettina Ugelvig Moller

The Nordic Project is a scientifically based research project of the personal experiences of people with Usher syndrome and how they handle the many challenges they are facing. Over a five-year period 20 people with Usher syndrome (type 1 and type 2) in Denmark, Norway, Sweden and Iceland were interviewed once a year by a deafblind consultant. The project was completed by the publishing of six booklets - each focusing on an individual topic - with the following titles: Theory and methods Receiving a diagnosis Getting support Being active Getting an education and work Narratives of everyday life Much too often, significant research results end up in a report on a shelf. There the report sits comfortably, but without having any real impact for the people which the research is about. This project was meant to have a practical impact on actions and decisions in the field - not because it holds any specific instructions on what could or should be done, but because it lends a voice to a multitude of statements about what it is like to live with a progressive vision and hearing impairment. One of the deafblind participants said regarding his involvement in the project: "A social counsellor only works with problems, for example transport. We never talk about my everyday life, my routines and my network. Before this project, I have never spoken about those problems either to a psychologist or to a social counsellor. They just look for a problem and then talk about it over and over again." In this workshop I will introduce the project and its outcome. What does it tell us about the lives of people with Usher syndrome, and what can this knowledge be used for - also in countries outside Scandinavia? The project was initiated and managed by the Information Center for Acquired Deafblindness. The booklets (in English) will be handed out during the presentation.

2770 Delivering Intervenor Services in the 21st Century

Program Models Suggestions for Improvement of Service Delivery

Oral Presentation

Catharine Proll, C Heather Marsden, Katherine Hesson-Bolton

Canadian Deafblind Association Ontario Chapter (CDBA ON) has been providing Intervenor Services across Ontario Canada for over 20 years. CDBA provides services for individuals in any life stage. We offer a broad spectrum of flexible programs and services for each segment of the population including individuals who are deafblind, families, children, adults, agencies and the general public. The organization has access to the largest network of Intervenors and industry professionals in the country. Since 2009, CDBA ON has been using a custom built web-based, interactive, electronic case management tool to provide efficient and effective services for our staff, families and consumers. Constructed for primary use by Intervenors and management, the tool quickly enables staff and families to access consumer plans and contacts; training and human resources materials, a financial management segment, and a consumer and employee schedule component with the click of a button. The web based program also generates valuable statistical data for management, government, and Board reports. Consumer documents including pictures, videos and critical medical data can be saved, and viewed, by the Intervenor services team. Organizational information such as policies, forms and training modules are stored and reviewed by all staff, assisting in the standardization of services and improvement of compliance with governmental requirements. Extensive privacy and security features have been built in to ensure that both staff and consumer information is protected. Serving Ontario, Canada's second largest province, covering more than one million square kilometres; using this tool, we are effectively impacting greater communications between management, Intervenor services staff, consumers and their families. Those located in remote areas, or at a distance from the service location, are able to enter or retrieve information directly from their computer at the same time that automatic updates allow for real time viewing by other intervention and management staff within the organization. This PowerPoint presentation showcasing CDBA Ontario's models of Service Delivery with our case management web based program will afford conference delegates a first-hand view of an improved service model highlighting individualized services, enhanced transparencies, and overall quality and standards so that "All people who are deafblind will live rich, meaningful lives".

2772 Transition of Individuals with Usher Syndrome to Adult Life--An Empowerment Perspective

Education/Rehabilitation Innovative Approaches for Children and Adults

Amos P. Sales

Rehabilitation and educational interventions leading to lifetime inclusion and empowerment of individuals with Usher syndrome will be discussed. The life of an individual with Usher syndrome is full of transitions. The transition to adult life, and the bridge of professional expertise from education to rehabilitation services, is one of the most significant times in the life of an individual with Usher syndrome. In recent years, rapid scientific advances in genetic research have further refined definitions and prognosis for the three types of Usher syndrome. Each type of Usher syndrome has different educational and rehabilitation challenges that must be addressed to meet the needs of each individual's life goals and place of residence. Each type presents variations in communication and travel skill needs that are also impacted by rural or urban settings. Scientific advances now permit diagnosis at birth affording opportunities for early educational intervention, rather than when a visual loss begins to be problematic, usually during teenage years. The three types of Usher syndrome also have specific implications for job placement and community integration that can be effectively addressed beginning during a child's academic years. The timely and coordinated infusion of appropriate skills and professional expertise can greatly enhance and ensure the independence, inclusion, and empowerment of children and adults with Usher syndrome over their lifetime.

2774 Intervention and Its Positive Impact on the Life of a Deaf Blind Woman
Education/Rehabilitation Innovative Approaches for Children and Adults

Oral presentation

Shari Chantler, Josie Quinn

This educational session will focus on the life of a 53-year-old congenitally deafblind woman Lynn Todd. Lynn spent 44 years of her life in an institutional facility where communication was minimal and interaction was limited. This presentation will outline the steps taken to successfully transition her to a community residential home at DeafBlind Ontario Services. Lynn's former mode of communication included self-injurious behaviours and loud, negative vocalizations. Lynn was often restrained physically and chemically as a management of these behaviours. On March 28th, 2010 through the Ontario Government's Facilities Initiative - Lynn was successfully transitioned to her first community home, in Kitchener, Ontario. Throughout this presentation, we will explore Lynn's current abilities and demonstrate the use of DeafBlind Ontario's current program module which has contributed to many of her successes. Through detailed use of the person centred approach goal tool, Intervenors, family and close contacts, have developed special goals for Lynn based on her dreams and desires. Lynn has also built and created many significant relationships with her Intervenors and family, as well as community partners. Through use of the program module's consistency, strategies, goal setting and planning we will illustrate the woman Lynn has transitioned to become today. Lynn strives for communication and to be communicated with. She marked her first communication milestone when she independently signed "more" and "tea" to her Intervenors on February 16th, 2010. Lynn is affectionate, funny and calm natured today, enjoying what her new home and DeafBlind Ontario Services has to offer her. Also included in this educational session, Lynn's successful moments will be illustrated through a photo montage. A handout will be available for conference participants. Please note that we have Lynn's parents support and encouragement to participate and share her story with the world!

2778 Triangelization on identity

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral presentation

Charlotte van de Molengraft, Sylvia van Doorn, Sonja van de Molengraft

Acquired deafblindness, not born being deafblind but acquired during life, has a great impact on one's life as he/she experiences losses. These changes in life and dealing with experiences of loss have influence on the basic assumptions of oneself and the world. This raises the question what the consequences of these losses are for one's identity. Acquired deafblindness means the person has to deal with a process of becoming deafblind. It can have multiple forms: he/she has been sighted and hearing or hard of hearing and sighted, or vision impaired and hearing, or any of the other possible combinations. The goal of this presentation is to give an answer to the question what are the consequences of acquired deafblindness for identity construction and how therapy can be improved to increase awareness of one's identity. This presentation has a unique set-up in that it takes into account the expertise and experiences of a person with acquired deafblindness, a rehabilitation therapist and a researcher. Through this so-called multi actor approach we want to address the topic on awareness of identity. We are all affiliated with The Kentalis Trainingcentre for People with Acquired Deafblindness in the Netherlands. This centre is aimed at (re-)learning independent living skills and supply them with social, practical and psychological support through intensive training. Currently, we are intensively searching for improving the possibilities of offering the right support and training. We are not only basing this presentation on practical knowledge and experience, but also on evidence-based research, as a colleague is currently attending the unique and internationally oriented Master in Education, Communication and Congenital Deafblindness at the University of Groningen. We would like to present the results of this research, that are based on practical expertise and empirical research. The latter was conducted through a case study. We argue that an increased awareness of identity of the person with deafblindness gives the professional tools to enhance the way he/she offers support. A part of the treatment is that we train people with acquired deafblindness to develop their own creativity. We have experienced that creative therapy is a suitable way to enhance self-confidence and self-esteem. Moreover, it provides them the opportunity to discover their "hidden" talents. We argue that self-confidence and self-esteem are two important components that are necessary in the process of awareness of identity. To illustrate the consequences and effects of this type of training, we conclude with first-hand experience of a person with acquired deafblindness. By sharing her experiences, it can give professionals insight in how her identity is developed, the influences deafblindness has on identity construction and the way creative therapy has given her insight in her own opportunities created for a lifetime.

2779 A Diverse Set of Services for a Diverse Population: Utah Ts System for Serving Children with Deafblindness, Birth to Twenty-Two

Program Models Suggestions for Improvement of Service Delivery

Oral presentation

Leslie Buchanan , Susan Patten

The population of students with deafblindness has widened in recent years. The Rubella Epidemic required new approaches to intervention and education and recent medical advances have further broadened the array of needed services (Miles & Riggio, 1999). The 2009 National Child Count of Children and Youth who are Deaf-Blind in the United States identified 76 separate etiologies for deafblindness. Of the 9509 children identified with deafblindness in the United States in that count, 4363 were identified as having one of the specified etiologies. 2272 have other hereditary/syndrome disorders, 645 other prenatal/congenital complications, and 583 other postnatal/non-congenital conditions. 1646 have no determination of etiology (The National Consortium on Deaf-Blindness, 2010). The diversity of the population of individuals with deafblindness requires a full continuum of educational options and services. Utah Schools for the Deaf and the Blind in the United States with the support of Utah Deafblind Project has developed a comprehensive system of services for children with deafblindness in early intervention and educational settings. This unique system of services has several key components. All children with deafblindness in early intervention and educational programs are assigned a deafblind teacher specialist. These specialists provide support to classroom teachers, early intervention service providers, parents, administrators, classroom peers, related service providers and community members. Deafblind specialists may: evaluate student need using appropriate assessments; implement accommodations, adaptations and modifications; provide direct services; provide training, consultation and other supports. If the educational or early intervention team decides there is a significant need resulting from deafblindness, a one-on-one intervener may be provided. Sixty to seventy percent of students receive the services of an intervener for at least some portion of the day; most for their entire school day. Interveners receive specialized, university-supervised training related to deafblindness and intervention strategies. They work under the direction of the deafblind specialist. Interveners: develop and maintain a trusting, interactive relationship to promote social and emotional well-being; facilitate access to information, provide ongoing access to receptive and expressive communication (Riggio & McLetchie, 2008). These services are provided in various settings, as determined appropriate by the educational and early intervention teams. The availability of specialized support based on student needs allows students to be educated in the most natural and least restricted environments. These educational and early intervention services are augmented by a successful family support program. The purpose of this proposed presentation is to share examples and strategies for providing the unique and diverse services required by this population. At the end of this session, participants will have an increased understanding of: · The roles of the deafblind teacher specialist, intervener and family support specialist · The continuum of service options from occasional consulting to full time intervener services with frequent direct services from the deafblind teacher specialist · Strategies for providing services in more inclusive environments through an appropriate system of supports.

2782 Longitudinal study of the behavioral development of persons with Congenital Rubella Syndrome

Research Scientific and Evidence-Based

Oral Presentation

Saskia Damen , Trees van Nunen

Congenital Rubella Syndrome (CRS) is a syndrome that can cause deafblindness and is often accompanied by medical and behavioral problems. Several studies show that people with CRS develop more problems as they grow older. In order to get an idea of the prevalence of health problems in their adult service users with CRS, two Dutch organizations, Bartiméus and Royal Kentalis, developed a CRS Health Watch Program. This program aims to monitor the medical and psychological health status of people with CRS. In this presentation, we provide an overview of the data collected since the start of the Health Watch Program in 2005, with particular focus on behavioral problems. We will provide a picture of the prevalence and development of behavioral problems since childhood, in 65 people with CRS. The longitudinal data such as presented are results of psychological assessments and a retrospective file study. Furthermore, we will discuss the usability and reliability of an inventory that was developed to systematically analyze psychological and medical files of people with CRS with regard to behavioral problems. After the presentation of the results, we will actively involve the audience in a discussion about the implications of our findings for both practice and research. An important question is if our findings are unique for deafblind people with CRS compared to people with congenital deafblindness and other etiology. Furthermore, we will discuss how changes in behavior of persons with congenital deafblindness and CRS can be understood and which factors contribute to changes within and between individuals. Finally, we will share ideas about future studies.

2783 Fostering High Quality Communication

Research Scientific and Evidence-Based

Oral presentation

Saskia Damen , Marleen Janssen , Wied Ruijsenaars

The communication between persons with deafblindness and their social partners is often characterized by low quality. Several studies show a high prevalence of misunderstandings, a lack of personal togetherness and mutuality, and limited variation in communicative functions and topics. The combination of both a lack of sensitivity of seeing-hearing partners to the communicative behaviors of persons with deafblindness and a lack of clarity and readability of these behaviors are believed to be both important components in low quality communication. In our study, an intervention program was developed, based on theories of the development of intersubjectivity (Trevarthen, 2001; Stern, 1985), the intervention model Contact (Janssen et al, 2003) and the work of the DBI ECN workinggroup (Master Communication and Congenital deafblindness, University of Groningen). The program aims to enhance the quality of communication between deafblind people and their communication partners. In this presentation we will give a detailed explanation of our intervention model and the way we applied the model in several case studies. Subsequently, we will involve the audience in the analysis of video-material, using the observation system that was developed to study the effects of our intervention model. Furthermore, we will present first results of the effectiveness of our intervention model on a) interaction quality, b) communication quality and c) partner strategies. After the presentation of our results, we will discuss the differences between the quality communication intervention and other types of interventions developed for interaction and communication and the limitations of the research we conducted.

2784 Confandi : sensory room experience

Program Models Suggestions for Improvement of Service Delivery

Oral presentation

Milena Londoño Patiño

The project I will present is called “sensory room”. It was created to support disabled people. It is a project developed by a private company from Colombia, named Confandi, which offers other services including health, education, culture and leisure.

This cultural centre offers library services to the community, including magazines, music, reading rooms, technology rooms, children rooms, exposition rooms, conference centre and a supporting place for disabled people. The main goal is to offer a support space for disabled people (deaf, blind and deafblind people) for them to access information and culture aspects.

2785 Portable Communicator for the Deafblind

Pesquisa científica e baseada em evidências

Oral presentation

José Augusto Fernandes Lopes, Shirley Rodrigues Maia, Maria Aparecida Ferreira de Mello

Communication plays a very important role in life. Activities like family relations, education, work, and other forms of social interaction are deeply dependent on efficient means of communication. Deafblind individuals experience an important deficit in communication ability that impacts their quality of life. Alternative and augmentative communication techniques available for the deafblind usually require great effort on the part of the individual and his or her communication partners. Many techniques, like the tadoma, are difficult to master, and are very demanding on the deafblind individual. Other techniques, like tactile signing or finger braille, also require extensive training of the communication partners. These techniques are also based on physical contact, which can represent an additional social barrier to communication. There are some electronic devices commercially available to simplify communication for the deafblind, but their cost is usually very high, making them unaffordable to most of the potential users, especially in low income countries. The main reason for this high cost is the use of Braille lines. A portable communicator for the deafblind has been developed, with ease of use and low cost as its main specifications. It is based on a 7-switch keyboard resembling that of a Perkins Braille, where 6 switches represent each of the 6 dots on a braille cell, while the additional switch is used to represent a space. The text typed by the deafblind individual is shown on a liquid crystal display to his communication partner. A response can then be typed on a regular QWERTY keyboard, and it will be transmitted to the deafblind user by vibrating those of the 6 switches corresponding to the braille representation of each letter. Instead of the Braille representation, only one vibrating switch can be used to send and receive messages using Morse Code, depending on previous training, cognitive and motor abilities of the user. The resulting device requires reasonable training on the part of the deafblind user, while being almost self-explanatory to the communication partners, who interact through a regular keyboard and read responses on a liquid crystal display. This makes it possible for the deafblind user to communicate directly to anyone, eliminating the need for an interpreter. In a second development phase, this device will be connected to a mobile phone with specially developed software. In this configuration, the mobile phone will provide a display and a keyboard for the communication partner. Besides being a portable and convenient interface device, connecting the mobile phone to the deafblind communicator will open many new possibilities, like sending and receiving text messages to and from regular mobile phones. It will also allow the use of location and navigation services based on GPS already available on mobile phones, but not easily accessible to deafblind users. This is expected to represent a very powerful platform for greater independence and should improve quality of life in deafblindness.

2786 The Life Space Model: Understand Perceptions, Identify Motivators, Enrich and Expand the World

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral presentation

Melanie Robartson , Fiona Kemp

Encompassed in the role of professionals working with children with deafblindness, is to collaborate with those who provide their care and education, to develop an understanding of the world of the child with deafblindness. While the family usually remains constant, there is a potentially large and changing staff, that also support the child, hence the need to share information about the child as quickly and effectively as possible. With its origins in the social psychological theory of the the 1930's and more recently in vision impairment literature, the term "life space" has been borrowed to help understand the experiences of a child with vision, hearing and quite possibly other sensory, learning and motor impairments. This model has served as a basis for the development of a tool for exploring the child's motivators and to use these to diversify their learning opportunities. It assists in the identification of their strengths and preferred learning style and can be an effective and efficient way of imparting a wealth of information about the child during times of transition. The "Life Space Model" explores the impact of the child's senses, including the vestibular system, encompassing the range of tactile senses, their internal state, motor development and socio/cultural setting to develop an appreciation of how the child with deafblindness experiences the world. The model has application to a range of conditions and can be applied across the lifespan, however the focus of this paper will be the application of the "Life Space Model" to congenital deafblindness.

2787 SESC Active Project: strategies of social inclusion of the person with deafblindness in leisure facilities

Program Models Suggestions for Improvement of Service Delivery

Oral presentation

Izabeli Sales Matos; Miguel Boaventura Fernandes Matos; Renata Rosa Russo Pinheiro Costa Ribeiro; Silvia Maria Nóbrega-Therrien

This paper describes the experience in the development of the SESC Project Active that takes place at SESC – Fortaleza. This program was implemented from the results of a survey conducted at SESC, whose target audience was people with deafblindness. We understand that the person with deafblindness has a unique disability because the limitation of both hearing and vision lead to significant losses that can influence mainly in the areas of communication and orientation and mobility. The research highlighted the need to implement the project aimed to investigate the contribution of aquatic psychomotor activities in the development of the person with deafblindness. The research is characterized as a descriptive and qualitative case study; the target population were three deafblind students who attend a public school in the city of Fortaleza and the instruments used were: analysis of reports and observation. After collecting and analyzing the results it was evident that aquatic psychomotor activities carried out with deafblind people contribute to the development of this individual, especially in the communication process, which is the basis for the inclusion process. Thus, from this result, we established the project in SESC, Fortaleza, the SESC Active Project (center of people with disabilities), which initially had only the subjects of this research and now has 60 students with and without disabilities with recreation and physical activity as strategies to promote social inclusion. Gradually we are expanding the users of the project and now we have people with different disabilities (blind, deaf, people with physical disabilities, intellectual disability, with developmental disorders and Down syndrome), and deafblind people and people without disabilities who interact each day, establishing social and affective relationships. Activities developed are: weight lifting, swimming, aquatic psychomotor activities, and excursions, theme parties and participation in social, cultural and sporting events. Through daily observation in the work developed and the report of those involved in the project (students, professionals and family), we observed the improvement of several factors that foster affective social relations and general development of the individual who are becoming more creative, participatory and thus enabling the social inclusion of these people, helping to improve their quality of life.

2790 The importance of rehabilitation for people with Usher Syndrome in Venezuela

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral presentation

Amarillis Sanchez

In 2010, Socieven located 146 individuals in Venezuela with Usher Syndrome . Most of these individuals were medically and functionally assessed by an Usher specialist. They also had the opportunity to receive rehabilitation from private and public rehabilitation centers throughout the country. When an individual with Usher Syndrome receives the rehabilitation program, the person will be taught basic skills required for daily living, as well as orientation and mobility and communication techniques. The client also receives psychological and social supports to help them use their functional vision and hearing and to live more easily within their families and their communities. When a young adult Usher syndrome person participates in the rehabilitation program they are given the tools to help them live life to fit their individual condition. They are taught to be able to accept their deafblindness condition, make life decisions, improve their self esteem, understand their capacities and abilities, be able to take care of themselves 'on the street' and try to live with less internal conflict. All these measures are meant to improve their quality of life and develop a level of independence to assist them with inclusion within the family, the work place and the larger social environment. Unfortunately in Venezuela, 97 % have not taken this rehabilitation opportunity, for various reasons. The reasons include: a general rejection of the idea of participating in this program; denying their condition; not wanting to face their situation because they fear they will be unable to live if their visual and hearing further deteriorates. This is unfortunate, considering that the intention of the rehabilitation program is to provide these individuals with the tools to help eliminate their anxiety and to demonstrate that "all things are possible".

2792 Transitioning to Adult Services- explore the possibilities

Families Supports and Partnerships

Oral Presentation

Ellen Faustman

Navigating from school into adulthood is an exciting time when all young people want to set goals and dream for their future. Young people who are deafblind and their families have the same ambitions, but the ground work to make this transition smoothly and effectively is one that needs to start early, while they are still in school. Come and learn how Deafblind Services Society of BC is striving to bridge this gap and developing tools and strategies to help families and teams succeed in a paving a path to ensure that the individual with deafblindness can follow their dreams and have a lives of meaning and possibilities. Learn how to:

- develop partnerships by involving the individual with deafblindness, their family, local service providers, school personnel and other key people involved to support their vision.
- develop a plan at age 15 and continue with this transition planning each year until age 19 and beyond
- how to involve and define the roles and task for transition planning amongst your team
- where to go for information and resources to assist you

This workshop will leave you feeling motivated and provide you with some ideas and tools to assist young people with deafblindness to move forward into the exciting world of adult services.

2798 Inclusion start at home

Families Supports and Partnerships

Oral presentation

Massiel Requena de Iriarte

One cannot talk about the life opportunities of an individual without knowing the family as a whole and to understand the influence or interaction of each family member. This is even more significant when talking about deafblind or multiple disabled people within the family. True inclusion starts within the family. It starts the moment the new member arrives. It functions through active participation of all its members in all of life's daily activities. But what happens if the new member is disabled and his or her conditions or capabilities are unknown by the family? At this opportunity I will review the family situation or dynamics upon the arrival of a disabled child. I should explain that the family's reaction may vary from one family to another depending on so many factors, including the parent's characteristics, their expectations, values, level of support, etc. Generally there are some emotions and feelings that lead to an emotional shock for the family. If the parents remain too long in this initial emotional shock they could lose the very critical initial stimulation time required for the new member. Knowing that the disabled child's inclusion begins at home, we will present expectations from some country families, to explain the barriers and the current state of resources that they have to access. These include locating organizations and institutions that will provide education, training and family support. Hopefully through this presentation, the families that have already "crossed the way" and those that are just starting this journey, will get the support, encouragement and tools to allow them to achieve the goal, that we all share: that our disabled children will become equal citizens with rights, be included in society and be happy.

2800 Usher Syndrome in Venezuela. A clinical and epidemiologic study

Research Scientific and Evidence-Based

Oral presentation

Paula Lucia Arreaza Vielma, Nelly del Valle Ramirez, Maria Luz Neri de Troconis

Objective: To determinate the clinical and epidemiological characteristics of people with Usher Syndrome in Venezuela. **Methods:** We researched the medical records of people whose hearing and vision tests at SOCIEVEN (Deafblindness in Venezuela), 2006-2010 to find those with Usher syndrome. The diagnose criteria for Usher Syndrome are neurological deafness and Retinitis Pigmentosa (RP). During the epidemiologic testing, we obtained the following information from each individual: age, sex, age when the visual and hearing loss first appeared, parents consanguinity or blood relationship (if any), family history on deafness or deafblindness. The ophthalmological tests obtained information on visual acuity, color vision, bio-microscopy, tonometry, ocular movements, and various retinal checks, including the electroretinogram, coherent tomography, formal field vision (Humphrey type or manual ones with a tangent screen). During the hearing test, the degree of hearing loss was confirmed and quantified. **Results:** Eighty-five confirmed Usher Syndrome individuals, found by Socieven through the “Socieven national network”, were tested. The gender breakdown was 61% female:39% male. The geographic origins of these individuals were as follow: Caracas (12%), Nueva Esparta (36%), Zulia (16%), Merida (24%), and other (12%). The parent’s consanguinity or blood relationship was known in 68% of the individuals. In 94 % of the individuals, the hearing loss symptoms (poor response to sound stimulus and slow language development) first appeared before the age of 3 years old. The ages when the low vision symptoms (night blindness, tunnel vision) first appeared were as follows: before 10 years old (24%), 10-20 years old (69%) and 20 years+ (7%). The age related change in visual acuity (20/200) was as follows: 0 – 10 years (0%), 11 – 20 years old (6%), 21-30 years (17%), 31 – 40 years old (39%) and 41 years old + (73%). Similarly, the vision field deteriorates with age. We found residual vision at 20 degrees at ages 0 – 10 years old, 15 degrees at ages 11 – 20 years old, 10 degrees at ages 21– 40 years old, and 5 degrees at ages 41 years +. Again, the incidence of cataracts and retinal opacity also increases with age.

2802 Do therapists have a role in the lives of people with deafblindness?

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Fiona Kemp

Historically services for people with deafblindness have been delivered by teachers and those with an education background. This is no different in Western Australia; but people with deafblindness in WA also have access to therapy staff that primarily service those with deafblindness. Senses Foundation offers speech pathology, physiotherapy, occupational therapy and social work to young children, school age children and adults under the 'Life Skills and Family Services' programme. The services provided are delivered using a person/family centred approach within the individual's home, school, day care, workplace or other such locations. While a transdisciplinary approach is used, each therapy discipline plays a specific role in the individual's life. This presentation explores the roles of each therapist and how these roles fit within the other services that the individual accesses across the lifespan. This presentation will also explore the results of a parent survey that explores the advantages and possible disadvantages of having access to therapists with training and skills in working with people with deafblindness and their families. The families surveyed have a child with deafblindness and have also received services in the past from therapists who do not specialise in sensory impairment. The role and skills offered by speech pathologists, physiotherapists, occupational therapists and social workers for people with deafblindness has often been forgotten. But for those with deafblindness and their families, these professionals can often offer services that can help promote skills and enrich their lives

2803 Actions against the inclusion of persons with deafblindness in terms of communication and access to information; Polish experience.

Program Models Suggestions for Improvement of Service Delivery

Oral Presentation

Grzegorz Czeslaw Kozlowski

Barriers in the communication and access to information are the natural and well known consequence of simultaneous damage of vision and hearing - that is consequences of deafblindness. However, the supply to the appropriate aids, providing support of the person who is familiar with various methods of communication of deafblind (person known in some countries as intervenor or guide-interpreter, while others have otherwise) and legal safeguards governing access to such assistance and services help deafblind people breaking down barriers of communication and information. In this presentation I would like to submit the action taken in Poland to counter the communication and information exclusion. I would like to show them in several different ways. In terms of technology, I would like to show our work in the field to provide access to different technologies (such as shared internet connection, sound in theaters, etc...) In discussing our efforts to combat communication and information exclusion in legal, I would like to show our treatments, both at the micro level (ie. in relation to individuals), as well as macro level (ie, associated with the development of specific legislation or legal provisions, etc. ..) I would like also to raise the awareness aspect (what can / should be change, why and how), related to deafblind people themselves and to their nearest and farther surroundings. In Poland, lately has happened a lot and is happening all the time in this topic. So, we can share our experiences. They can be useful especially to those countries that are currently on the lower, initial stages of the integration of deafblind people in the mainstream of social life, by assisting them in overcoming barriers to communication and information.

2804 Looking beyond sensory impairments: A unique and innovative Multidisciplinary approach for early intervention in a hospital set up.

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Ms. Sampada Shevde ,

Early diagnosis and effective intervention can significantly reduce the incidence and negative developmental impact of deafblindness. Yet a few medical or rehabilitation organizations were found to be equipped to meet these needs in children with deafblindness in India. Focusing on this population may mean selecting a group that is not likely to yield the dramatic figures that interventions in single disability will. However, if we believe in every individual's right to a good quality of life, numbers should not influence our willingness to take up this challenge. With this underlying philosophy, the Early Intervention Center and Diagnostic program in Tripolia Hospital in the state of Bihar in India is an innovative program designed to provide medical, emotional and educational support and specialized knowledge from trained medical staff and educators to parents of infants who are deafblind. This program has been designed to: Help make connections with at-risk and newly-identified infants and families who are often lost to follow through services after newborn screening and/or diagnosis. Provide a cadre of parents who have been trained by educators to support families towards modes or methods of communication or educational programming Mentor families through the early intervention years through knowledge of early intervention and educational systems. Expose families to diverse models of communication which are totally need based for their own children This unique approach of combining medical intervention with emotional and educational intervention is a ray of hope and a huge means of support to many families and infants with deafblindness and will surely be a model for many other rehabilitation centers to replicate in various parts of India.

2805 Deaf blindness and dementia

Program Models Suggestions for Improvement of Service Delivery

Trine Skov Uldall, Karin Moreau Andersen

Oral Presentation

Deaf blindness and dementia - Related symptoms and neuropsychological testing by a newly developed tactile test battery This workshop aims to focus on deaf blindness and dementia. Citizens over 80 years of age form the largest group of persons with acquired deaf-blindness in Denmark. They typically suffer from age-related hearing and vision impairment. Researches show that one out of every eight people at the age of 80 suffers from dementia. Among the group of people at the age of 90 it applies to every fourth. The number of demented persons and the number of elderly with acquired deaf blindness will grow significantly in the years to come for the simple reason that the number of senior citizens increases. In our daily work as deaf blind consultants we often meet people with acquired deaf blindness that are experiencing massive difficulties in maintaining their level of function as well as an active, social and meaningful everyday life. Occasionally we wonder whether this is only caused by the consequences of deaf blindness and with that, isolation, or whether we are dealing with cognitive problems perhaps due to an incipient dementia. It can be hard to distinguish. Another Issue is that parts of the regular neuropsychological test battery, testing for cognitive dysfunction, require a functional sight and hearing. Thus, during the last couple of years we have in our group of deaf blind consultants in Denmark been concentrating on the following issues: - How do we distinguish between difficulties caused by the dual sensory loss from difficulties caused by the combination of dual sensory loss together with an incipient dementia? - Which consequences do the combination of deaf blindness and dementia have in relation to everyday life? - Development of a tactile test battery to accomplish existing test batteries. During this workshop we will inform about our work and experiences in relation to the above-mentioned issues. We will present a new tactile test battery developed by the Danish neuropsychologist Peter Bruhn. We have worked with Peter Bruhn on testing this very new tactile material, and will like to share the interim experiences from this work and thereby prepare the ground for exchange of experiences and for dialogue about deaf-blind people with suspected dementia.

2806 Supplementary Aids and Services Toolkit for Inclusive Educational Practices

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Kristen Parsons

The State of Pennsylvania is dedicated to the inclusive educational practice of students with complex support needs including children with Deaf-Blindness. Pennsylvania is committed to ensuring that Individualized Educational Planning teams begin with the general educational setting with the use of supplementary aids and services before considering a more restrictive environment. The Supplementary Aids and Service Toolkit was developed in response to the Gaskin Settlement. The settlement comes after ten years of effort in a state-wide class action called *Gaskin v. Commonwealth of Pennsylvania, Department of Education*. The United States Department of Education reported that Pennsylvania was the seventh lowest state in 2002 for including students with disabilities in regular education classrooms. It was created by Dr. Gail McGreggor of the University of Kentucky, the Bureau of Special Education, the Department of Education, and the Pennsylvania Technical Assistance and Training Network. Through the process of the Supplementary Aids and Services Toolkit, Individualized Education Program teams can focus on the strengths of their student and how to incorporate those strengths into the general education curriculum without focusing on their disability. The Supplementary aids Service Consideration Toolkit consists of five components that are designed to facilitate ease of use. This planning team includes but is not limited to the parent, the student, the general education teacher, the special education teacher, related service providers, principal and/or school district representative. We would like to present the SaS Toolkit at the conference and describe the benefits that the tool provides when considering placement for students with Deaf-Blindness in a general education classroom. The state of Pennsylvania has found successful inclusion occurs when mindful planning takes place.

2811 A study the location and characteristics of deafblind and multiple disable people in Chile

Research Scientific and Evidence-Based

Oral presentation

Lucia Millán Briceño, Felicia González, Oriana Donoso

The major purpose of this study was to determine the characteristics of deafblind and multiple disabled people in Chile. We wanted to determine the location of these individuals, the etiology of their condition and learn about their level of access to education and other services. Another purpose is to improve the quality the current statistics to have better information about where these individuals are located. A further intent of the research was to assist in the formation of national policies to deal with the needs of these disabled people. The first part of the research was to carry out a census of this population. To do this census, we established a research design to undertake a virtual survey through the webpage of the Chilean Education Ministry.

2813 Begin with Family: Building blocks of Inclusion in context of children and adult with deaf blindness

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Vaishali Kolhe

The Building blocks of inclusion begins from family Inclusion first. This goes ahead and transform into a Lifetime of Opportunities in lives of children and adult with deaf blind. While working in the school for deaf blind, it was realized that during vacations the children do not want to go home, moreover the families are also not very keen enough to take them back for few days. This body of knowledge is unexplored in the field of deaf blindness population. My study highlights the nature of relationship between child and adults with deaf blindness and their families. A critical enquiry made into this problem, which became my research question to work on this paper aiming to find out ways to bridge the gap between family and child and adult with deaf blindness . First part of the study attempts to comprehend the child's point of view and family point of view in complex family systems, followed by studying the interaction between the family and their ecological milieu. Second part of study views family as an unexplored resource for developing inclusion in context of family and its subsystems. This facilitates the ultimate goal of inclusive education and inclusive society at large. Third part of my study is to develop a family partnership model for the school /institution with the principle approach to view family system in totality as a unit of intervention and how each family subsystem (sibling, parent, grandparent subsystems) become partners for overall intervention with the institutions /schools. The qualitative study ranged from assessing the families of children and adults with deaf blindness by understanding the main characteristics of family interactions comprise of cohesion, communication, role performance, decision-making and adaptability to preparing family partnership model of practice by schools and institutions. The study examines and critically integrates theoretical concepts of family system and family interactions in context of children and adult with deaf blindness. Key words: Inclusion, Family unit, Family structure, Family subsystem, Cohesion, Family interaction.

2814 Teacher training focusing on best practices according to the functional needs of the deafblind student in Ecuador

Myriam Mariana Gallegos Navas

Since 2005, thanks to the support of Perkins International, deafblind and multiple disabled students have had access to education in Ecuador. One of the factors that allowed their successful integration has been the teacher training and the pedagogic support provided to improve teacher practice. Prior to this new support, the teachers worked only following the general curriculum, with some adaptations and support through physical, language and occupation therapies. These adaptations did not take into consideration the individuals development and communication needs. In other words the adaptations were done without seeing the child as a “total person”. We changed the teachers’ practice in a more productive way; allowing the students to learn in a more functional way and permitting them to be more included in their community. We can say now that this new teacher training has resulted in a 40% improvement in the results for students. Having learned these functional education concepts, the teachers now plan the student’s education according to their individual needs.

2820 Inclusion of students with Multiple Disabilities

Research Scientific and Evidence-Based

Oral presentation

Susana Maria Mana de Araújo , Maria da Piedade Resende da Costa , Andreia Mendonça dos Santos Lima

The aim of this research was to analyze the effectiveness of the implementation of a Support Program for Inclusion of Multi Disabled Students using techniques such as MAP and PATH as facilitators. The techniques disclosed by Pearpoint, Forest and O'Brien proposed a centered work on the person that acts with a positive vision of the future, where is developed by groups in which families, professionals and community members participate. The participants were four students between 7 and 14 years of a specialized institution and they began to be a part of the category of "participating beneficiaries." On the groups worked: four 'facilitators participants 1', family members; four "facilitators participants 2", professionals of the specialized institution; and four "facilitators participants 3", members of the general community. It was proposed and carried out three meetings to develop the technique MAP for the removal of the needs and characteristics of each "participating beneficiary", that aimed a plan of action. There was full involvement of participants. Six meetings were proposed with the PATH technique for monitoring the actions, and six meetings happened in a group, five in another one because of the difficulty of one of the members, and four in two other groups because of problems in accessing roads. Requirements were raised to improve the educational programs to encourage the development of communication, activities of daily life, inclusion in regular schools, inclusion in the general community, the need for diagnosis, family support and effective relationship between education and health areas. The actions performed successfully forward improvements in care of the specialized institution, getting first an online advice and later, a presence advice with a three-day seminar for parents and teachers which were all subsidized by national and international institutions. It was started a work on monitoring activities of daily living at home and social inclusion in areas of "participating beneficiaries" focusing mainly the churches that were available. The diagnoses were scheduled in a philanthropic hospital that provided a predictable treatment and it was got aids of volunteers, so the families could travel to the state capital for these services. Three of the "participating beneficiaries" sought the regular education system, where only one got registered but he could not attend for lack of educational help. It was initiated in this case, a work in partnership between management, teachers and the school's specialized institution, volunteers and the researcher to achieve the inclusion. It can be concluded that the techniques MAP and PATH facilitated the actions to improve the family, social and educational inclusion because they followed the plan. It is desirable that the groups would have a greater number of members and that facilitators of the community could join to the centered group on the person and also to a group of volunteers to maximize the overall effectiveness of actions. Also, the partnership achieved through the regular school, in a case could be extended to all, encouraging the exchange of shares between the regular education, special education and health services.

2822 A proposal for staff training to enhance inclusion in the classroom

Education/Rehabilitation Innovative Approaches for Children and Adults / Inclusive Education

Oral presentation

Gabriela Alejandra Martinez

Based on the needs of those students with multiple impairments now included in regular classrooms, we provided academic space to train staff in special education. Training in special education was added to the qualification requirements for teachers. This is deemed essential to promote the inclusion for the education of students with multiple impairments.

2824 Federation of Latin American families of deafblind people and/or multiple disabilities: Seeking common goals in search of improvements in quality of life

Families Supports and Partnerships

Oral Presentation

Aurea Maria Soza, Susana Maria Mana de Araoz

The formation of parent groups has been very efficient to get to meet the needs of the families of the deafblind people and/ or with multiple disabilities all over the world. The first ones appeared to get educational attention that there was not there and the other ones made it to support care enterprises that states or private institutions made to meet demand. In both cases, parent groups were the ones that got, in a more genuine way, the understanding of the anxieties of the first moments from the psychological point of view, going through the search of knowledge and the struggle for the rights of their children, which also are designed as family rights. These groups were organized in associations or not, they spread through Latin America supported by International Perkins that was aiming a performance that put synergy to the actions that took them to a meeting with representatives of 12 countries in Latin America, in Cordoba, Argentina, during June of 2010. As a result, they got to a proposed action in groups of countries, divided into four regions that were going to be coordinated for existing organized associations that were in Argentina, Brazil, Guatemala and Venezuela. This meeting was a milestone in the history of the ways walked together by the associations or parents groups that were there and they showed how they completed and sustained the actions on time, and they decided for a formation a Federation. In six months, each country representative executed the necessary contacts for the formation of a group of parents in their country to convert existing groups in an association, aiming at the Latin American Federation. This work was made with the assistance of the coordinator of the group, through the Internet, who stimulated, with material and ideas, the development of actions. These actions were parent meetings, discussions about goals, meetings with authorities, community actions as lectures, marches, commemoration of the day of the person with disabilities, and others. The activities resulted in an agreement of purposes to finish the associations off in several countries, getting closer the meeting of the objective of the Federation of Associations of Parents of Latin America. All efforts of the regional coordinators were coordinated and stimulated with the support of management tools offered by the general coordinator from the regional office of Perkins International. The authors as mothers of the deafblind young people have come a long way, creating services, facilitating the work of the families, investing in specific training and in organizational management training. At the moment, they chose a great challenge of facilitating the parents training so they can in an organized way to continue guaranteeing the conquered rights and proposing the formation of new leadership.

2825 “Ouch! Pain expressions in CHARGE. Interpretations within a communication and partner competence perspective”

Staff Development Effective Models and Creative Approaches

Oral presentation

Ulrica Broddstedt

This presentation will focus on our experiences with staff supervision, in particularly with staff working with congenitally deaf-blind individuals with CHARGE syndrome having communicational difficulties and showing possible signs of pain expressions. Recent research has indicated an increased risk of pain in individuals with CHARGE syndrome. The objective of the staff supervision is to expand the awareness of the non-deafblind communication partners awareness of the pain expressions of their congenitally deafblind CHARGE partner. Through an increased knowledge of CHARGE related pain behavior and overt communication of pain (such as body movement, posture and vocalization), as well as an increase in the confirmation of the deafblind CHARGE partner`s pain expressions, a better understanding and interpretation of the bodily-emotional expressions of distress could be reached. The Nordic CHARGE network has a collaboration project about CHARGE syndrome and pain. The reason to initiate the project was that congenitally deaf-blind individuals with CHARGE syndrome uses expressions such as self harming and/or complete lack of - or delayed pain reactions. These expressions may be difficult for the communication partner to interpret, confirm and communicate about. In the presentation we will be following the non-deafblind communication partner's process in the supervision regarding CHARGE syndrome and pain. The presentation is focusing on the procedures before, during and after the supervision. Through systematic communication analysis the interpretation of expressions increased during the supervision. The partner's new interpretation seems to lead to an increase in the partner awareness of the pain expressions of the congenitally deafblind CHARGE partner and to a better management.

2826 Challenges bringing innovation and evolution: changes in deafblind population and the answers of a resource centre

Educación / Rehabilitación Innovativos, atención para niños y adultos

Maria Aparecida Cormedi, Maria Teresa Borro, Helena Burgés Olmos, Ana Maria de Barros Silva

This paper presents the results of a survey of statistical data and discuss the population of deafblind people which has been changing. The results shows analysis of 700 students cases including infants, children, youth and adults during 28 years of Adefav existence in Sao Paulo, Brazil. Founded in 1983 as an association for deaf blind people to attend special school, currently Adefav is a resource center on multiple disabilities, visual impairments and deafblindnes sand changes occurred gradually at the same time we developed educational work to accompany the change of population, public policy and new philosophical approaches related to specialized care in education and rehabilitation. In the 80 most cases of deafblindness at adefav was caused by congenital rubella syndrome. In the 90s, influenced by the Salamanca Statement, the movement has expanded to build an inclusive school, as well as to increased criticism of the consolidated modes of action in special education and reporting of the most innovative experiences of educational inclusion of people with disabilities in regular schools. Another change came when the families of children with deafblind with multiple disabilities and other disabilities have to seek the services of Adefav. It was necessary to seek new knowledge to face the challenger on new population. We will present the analysis of 700 cases classified as deafblind, disabled and deafblind with multiple other disabilities organized by etiology, age and length of stay in care and the number of professionals involved. Such statistics also indicate the changes of policies and various forms of direct intervention with children and adults as well as organizational and management changes that led to different intervention programs. From 90's in Adefav, there was an increase of children with deafblindness and other disabilities associated with increased number of premature infants from the year 2000, which corroborate with the increased number of premature infants and children with syndromes that survive due to advances in medicine and technology resources. Another factor discussed in the analysis refers the intervention strategies and the pursuit of new knowledge that were needed to meet the educational needs, health, communication and mobility of this new perspective of the population in inclusive education. The result is a new organization that assimilated population change and created a model resource center following guidelines of the Convention on the Rights of Persons with Disabilities. The evolution and history of Adefav reflects the history of evolution and education of persons with deafblindness in Brazil.

2838 Different deafblind syndromes New diagnostic tools and treatments

Research Scientific and Evidence-Based

Oral Presentation

Claes Moller

Deafblindness is a group of very heterogeneous disorders. Around 100 different deafblind syndromes are known today, although many of them very rare. A very rapidly increasing knowledge is at hand, especially in the field of diagnostics, genetics and molecular biology. New findings of genes, mutations and proteins is rapidly giving rise to treatment options of both retinal and cochlear dysfunction and eventually cure. This presentation will focus on the importance of making a correct and early medical and functional diagnosis, by using state of the art clinical and genetic methods. Examples on difference and resemblance between different syndromes will be given along with the latest genetic discoveries and presentation of ongoing genetic treatment trials.

2839 Intervention Strategies Resource Centre for the success of inclusive education of children with deafblindness and multiple disabilities from 6 to 12 years.

Staff development, models for developing effective and creative approaches

Oral Presentation

Ana Marcia F.C. de Jesus, Agatha Fontes Bago, Maria Teresa Borro

This work intends to provide intervention strategies and activities in Inclusive Education and the media used for students attending in-Adefav Resource Center on multiple disabilities, visual impairments and deafblindness, in Sao Paulo, Brazil. The project will be displayed in the program of special classes held in 2010 and 2011. Accompanied 25 students are being classified as deaf and blind, deafblind with multiple disabilities and other disabilities enrolled in regular schools and special schools, and attending special classes under the counter-round Adefav that performs the monitoring of these students in schools. Children with multiple disabilities or deafblindness associated with other disabilities have specific problems resulting from conjugations and limitations on the functions and body structures and environmental factors that can hamper their development and functioning of the sensory channels of information, affecting learning ability and troubleshooting. To enable the inclusion of these children was created with an inclusion model of Perkins International financial subsidies and covenant with the City Department of Education - São Paulo (EMS). It consists of the presentation of this work: Collaborative Team training, creation of specific instruments to assess functioning school, the survey forms and communication needs of learners, a description of actions taken in special classes, activities at the municipal bodies of inclusion, Cefais as well as the activities and guidelines for the regular school and family; adaptations and supports that students need to be effectively included in mainstream school and finally to share information from the regular school, the Educational Center of Specialized and family to jointly develop the Plan Individual Education (PIE) of students by ensuring access to the regular curriculum and its alignment.

KEYWORDS: SPECIALIZED; SCHOOLING; INCLUSIVE EDUCATION.

2840 Success with inclusion in Guatemala

Carmen Lucia del Pilar Guerrero, Abascal de Prado

To think about inclusion in a multi cultural, plural ethnic, multi lingual country, where the individual differences and population inequality is a characteristic, is to think in a utopian or idealistic context! The culture in Guatemala is not an “inclusive culture”. For that reason it was difficult for the people to understand that inclusion is a right, and a situation where all children, depending on their needs, could share a classroom and be an equal part of it. Initially this was a utopian idea; but now it is a reality that is beginning. FUNDAL started a process to facilitate inclusion from a Guatemala context. The process took into account each student’s characteristics, their family, school and community. This process included participants from the education ministry, the school and the family. For the inclusion we developed an individually based educational planning approach based on the national curriculum and *using the programs called* “quality of life skills by COACH (Giangreco, Cloninger and Salce Iverson) and the bear/star process (Perreault and Bove)”. These first experiences permitted change in the educational system in Guatemala. It opened the doors for a more equal world for all; where the main barrier is not the disability but the social environment that makes the disability a barrier.

2844 Janine story: a congenital deafblind going to the full inclusion

Education/Rehabilitation Innovative Approaches for Children and Adults / Inclusive Education

Oral presentation

Sandra Samara Pires Farias

The last twenty years of the XX century were signed by big changes in what is related with the disabled people attention. Those changes were on legal aspects, through laws, declarations that emphasize the importance of respecting the diversity of the human being and the education, the health, the free time rights as well as the opportunity to become a professional. Another important change was the education inclusion for disabled student. Our constitution guarantees the education and inclusion to the school for all, does not matter the race origin, race, color, sex, age, disability. The main focus of this work is deafblindness a theme that was delicate and not explored in Brazil. It is very important related with the full development of a deafblind person, showing her life story, her possibilities, abilities and potential. The interest on this issue came when my daughter Janinne was born deafblind. And because deafblindness is very unknown for the education researchers as well as in the Brazilian society, as a proof is that the education ministry developed some publications for the special education attention that offer the guidelines for the teachers to offer the education inclusion conditions and opportunities at the mainstream schools. Those publications (one for each disability) include all disabilities except deafblindness. On this context I am describing Janinne life story, from her birth to 18 years, her education process until the first secondary level as well as her social inclusion with emphasis on the sign language as a main communication system. This presentation is based on the theory research and become a hope and commitment message to build a new paradigm of respecting the diversity and recognize it on the human relationships. The discussions done here are based on the ideas of the following authors Lagati (1995), Araóz (1999), Amaral (2002), Maia (2003), Cader-Nascimento & Costa (2005) Van Dijk (1986), Serpa (2000). Finally this presentation considers the research of the life story of a congenital deafblind person with all the difficulties that came from the deafblindness, specially on the communication and to know that through the tools offered it is possible to communicate, to have fun, to have responsibilities and to live well and how the disability is not a condition that determines her life story as a disability

2847 Foundations of meaning and senses: the acquisition of language in congenital deafblindness.

Research Scientific and Evidence-Based / Communication and Language
Maria Aparecida Cormedi; Elcie F. Salzano Masini

The deafblindness refers to the condition of simultaneous deficit of hearing and vision which causes a sensorial deprivation of senses responsible for receiving information from a distance, such as: temporal, directional and symbolic information. In Deafblindness the visual sense does not compensate hearing deficit and auditory sense does not compensate for visual deficit. The sensory compensation occurs through the sense of touch and proprioceptive system, which includes the kinesthetic and vestibular senses. Deafblindness presents one of the greatest complex perceptual issues: the specificities of each deafblind person communication and language acquisition. This thesis proposed: to research the trajectory of two young girls who were able to compensate the deafblindness, acquiring language and communication by sign language, revealing the communication challenge, from the standpoint of those people who have overcome it. The objective was to identify factors that enabled the acquisition of language and the communication by sign language of two young girls with total congenital deafblindness. The methodological approach was a case study of each one of the two deafblind girls, in qualitative modality. The innovation of this research was to interview directly two deafblind young girls and their families, professionals, complementing these data with records of direct observation and document analysis. The theoretical concepts were based in different authors according to themes: referring to deafblindness – Alsop; Brown; MacInnes; Orelove; Riggio; Sobsey and Treffry; referring to language and communication interactionism social and cultural approach of Vigostski and Bakhtin; referring how to place in the environment, understanding world and communicating - Amaral; MacLinden; Masini; Miles; Reys; Sacks. This thesis has described and analyzed the relationship of two total deafblind young girls with others and their environment as well as to describe and analyze their processes of language acquisition and linguistic communication. Data analysis has identified the stages from pre - linguistic communication to linguistic forms, as well as factors that enabled the acquisition of language and linguistic communication, highlighting their linguistic modes of communication – tactile sign language, sign language and Tadoma. The results showed the foundations factors to language and communication by sign language of the two young girls who were total deafblind surveyed: the assumed identity as a deafblind person; the development of sensory and motor skills; the historical family, educational, social, cultural environment; the opportunity to have a mediator; the relationships with other aware of their forms of communication expressive and receptive communication. Key-words: deafblindness; language; communication; interactionism; sign language

2850 An Overview of Successful Strategies Used to Improve Communication and Information Access for Individuals With Combined Vision and Hearing Loss in the state of Arizona, USA

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Edward K. Gervasoni

For individuals who live with combined vision and hearing loss, accessing the community may often be a frustrating, exhausting and unsuccessful venture. Community environments range from simple to complex and static to dynamic. The more complex and dynamic a given environment, the greater the need for making adjustments for such individuals to successfully gain access to communication exchanges and available information. This presentation addresses successful strategies that improve communication and information access for individuals who have various forms of combined vision and hearing loss as they participate in community activities within the state of Arizona, USA. The overall strategies addressed are in the areas of self-advocacy, specialized service provision, and assistive technology. This presentation specifically explores: (1) self-advocacy strategies such as a personal understanding of one's vision and hearing functions within given situations and environments, understanding given environments as they change from simple to complex and using successful methods for taking control; (2) specialized service provision including strategies for using volunteers and professionals to help gain access to information and fill in communication gaps; and (3) assistive technology such as equipment used to enhance hearing and vision capabilities within functional settings. Participants will have opportunities to view video clips in which individuals living with combined vision and hearing loss discuss and demonstrate successful approaches that address their particular communication and information access challenges in various situations

2851 Plus and Minus - beneficial or inhibitory effects of encounters

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

P O Edberg , Cecilia Joge Johansson , Gerd Nylander

What may the beneficial as well as inhibitory effects of encounters with the professional world, with school/work and social life be for people with acquired deafblindness? Could well-intentioned efforts in fact have detrimental consequences over time? Considering the individual from a life perspective, what specific initiatives, actions or situations may be of particular importance? Could any common advantageous factors that may apply to others in similar situations be distinguished? Do professionals in their encounters with persons with deafblindness have a propensity for categorisation and generalisation due to their own, at times narrow, professional perspective? If so, what could the consequences of such premises be? The numerous questions we focus on are largely related to various events in relation to life changes and to the necessary transitions required for people with acquired deafblindness. In the last 30 years, we have seen a development in the support people with deafblindness receive from professionals in Sweden. This is another interesting aspect that we also wish to highlight. In order to pursue these questions, we initiated a series of interviews with 15 adults with acquired deafblindness in the 24-69 age group. The chosen interviewees can be described as a heterogeneous group with varying abilities, background and age, residing in different parts of Sweden. When analysing the interviews we were particularly interested in beneficial and impeding factors that affect people with acquired deafblindness, however, we also focused on the impact these factors have in the life transformation that acquired deafblindness demands. The interviewed subjects' experiences can be summarised in four main areas: When life changes Rehabilitation Social life Working Life The above areas were further highlighted in conversation with each participant. These conversations primarily took place in the interviewee's home. We compiled the responses to the interview questions based on perceived beneficial and impeding factors alongside relevant quotes and excerpts. We consciously sought to compile the collected information in a manner that refrained from 'staining' the inquiry with the perspectives and attitudes our professional backgrounds may cause. The study was named Plus and Minus. The responses we received from our participants have shown us in the professional field that humility is the best policy, and highlighted how just far our own reality often is from that of a person with acquired deafblindness. We have also received comments from the interviewees that confirm that the report conveys parts of the reality life with acquired deafblindness entails. We would like to share these findings and what we have learnt with others.

2856 THE USE OF AN INSTRUMENT: EVALUATION PROTOCOL FOR THE DEAFBLIND AND MULTIPLE SENSORIAL DISABLE STUDENTS AT THE SCHOOL BASE ON LAVELLE DOCUMENT

Program Models Suggestions for Improvement of Service Delivery

Oral presentation

Shirley Rodrigues Maia ,Vula Maria Ikonomidis , Sandra Regina Stanziani Higino Mesquita, Marcia Maurilio Souza, Susana Maria Mana de Araoz

Since 2009 we had a technical cooperation Alliance between Ahimsa and the Municipal Education secretary of São Paulo, to train collaborative teams looking for the inclusion of deafblind and multiple sensorial disable, with the necessary resources and supports. After the training we plan a visit timetable for the schools that are in Alliance with the CEFAIS Education and training centre for the inclusion support to look for the practice. From this meetings developed through the instrument called “Evaluation protocol for the deafblind and multiple sensorial disable access to the school and stay in it” based on the instrument called “the inclusion of children and young deafblind and multiple sensorial disable- reflex ion of the working team” . This instrument also called simply “Lavelle document” for the reference of the project support by Perkins International. To know the adequations needs and the visit and following timetable we had meetings at 8 schools. For the Ahimsa team were selected the schools that has deafblind and multiple sensorial disable students in the first years and children education with the support of professionals from the Cefais, pedagogy coordinator, teacher, praticias and direction. A following was done at the school activities and discussed after the meetings where the student needs and goals at the school, the education attention, the Cefai support and families orientation. As a result we got an Alliance with the Special education attention that support the development and learning of deafblind and multiple sensorial disable children and Young. Modifications were done for the intervention looking for the student best. We can conclude that the used document has the conditions to improve the work done by the collaborative teams for the inclusion of the DEAFBLIND AND MULTIPLE SENSORIAL DISABLE students.

2857 A tactile approach to communication

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral Presentation

Aase Aune Endresen

Can more focus on tactile strategies enhance communication development for individuals with congenital deafblindness, even for those with residual sight or hearing? To what extent do we, as partners for persons with congenital deafblindness (cdb), support their development by adapting to their intact senses? Are we too dominated by our intact and dominating senses, and thereby restrict meaningful sensory impressions in social relations? Do we utilize the tactile senses, senses dealing with touch and movements, good enough in intervention, or do we overestimate the functions of a reduced vision or hearing? A change in intervention has opened for considerable progress in communication development for children and young adults with cdb. A more tactile approach has been an important factor of this change, but the new understanding of communication development that has been achieved in Europe the last years, has also been basic and of crucial importance. Examples of interaction between individuals with cdb at different communicative levels and with different degrees of residual senses and their partners, will be presented and discussed. The focus will be more on what the partners are doing in order to be better tactile communication partners, than on the skills of the person with congenital deafblindness. In one of the of the cases, a high level of communication has been reached, which we seldom see in the deafblind population, and this persons reflections on what is important for a successful communication between him and his partners will be highlighted. The examples will be illustrated by video clips and narratives.

2861 University and Rehabilitation: Accessibility to the deafblind

Education/Rehabilitation, innovative approaches for children and adults

Oral Presentation

Patricia Muccini Schappo

This work refers to the extension project from the Universidade Federal de Santa Catarina - UFSC and from the Associação Catarinense para Integração do Cego - ACIC, elaborated by the pedagogical coordination for the Letter Libras course in conjunction with the supervision of subjects of inclusion from UFSC. Such project has as main objective to promote the accessibility of the deaf blind to the higher education area and in the activities of an autonomous life. The project starts from the principle that the University should have a democratic space that seeks to answer all learning needs for all students, with no social, cultural, ethnic, gender distinction or as a reason of physical handicap and personal characteristics. The project's basis is the conviction that all individuals, regardless of his/her personal characteristics, have conditions to learn and self-develop, considering his/her main needs are understood and attended. It's understood that the University should seek everyday for its improvement considering the quality in the service rendered and for that to happen, it's of paramount importance that the interventions, next to the students with physical/mental handicap or learning disturbances, be of multi-professional aspect, crossing over the classroom, where there might occur curricular adaptations that aim at attending each student's needs. In order to do so, necessary actions such as: forming a study group with professional educators to establish a dialog about issues about deafblindness and promote attendance to the deafblind through alternative communication activities. The methodology used consisted in systematizing weekly meetings for the study and discussions about issues that involve deafblindness, with the purpose of capacitating professionals to attend the deafblind. Since the project is under way, considering that the work shall accompany all the trajectory of these students when in higher education, the results already obtained are: The permanence and effectiveness in the quality of education, the access to independence and autonomy through the partnership with rehabilitation, as well as , the learning of many kinds of communication, unknown to the deafblind up to then. Key words: Inclusion, Deafblindness, Higher education, Rehabilitation.

2865 Perception complemented by technology

Eduardo Jaramillo Rodriguez

This paper describes an IT service available for blind people in Caracas that was modified for use by people who are deafblind. The service is explained through the experience of a deafblind lady name Myriam Torres.

2867 Theory-of-mind in young adults with Alström - a deafblind syndrome.

Research Scientific and Evidence-Based

Oral Presentation

Hans Erik Fralander , Claes Moller , Berit Rannasen

This is a presentation of one part of an ongoing study concerning cognitive functioning in young adults with Alström syndrome, an autosomal recessive deafblind syndrome, also including other affected organs. Development of Theory-of-mind (ToM), referring to an ability to understand self and others, is of special interest. Previous studies have demonstrated delays in the understanding of ToM in deaf late signers as well as children and adolescents with blindness. Clinical observations also suggest a higher occurrence of deviances in the development of ToM in Alström syndrome. It could hypothetically be syndrome related but also secondary effects of dual sensory loss. The performance of 12 adolescent over the age of 16 with Alström syndrome was examined, using "Strange stories", a test of the ability to understand story characters' thoughts and feelings. A comparison is made with age matched non-syndromal individuals and individuals from other specific populations. A first analysis reveals both similarities and differences within the Alström - group and in relation to the control groups. The patterns of result are discussed in relation to medical factors and hindrances in daily life - and with references to contemporary cognitive theories

2869 Dental Health Care

Program Models Suggestions for Improvement of Service Delivery Oral Presentation

Griatte Griffioen

De Brink, part of Royal Visio, is a residential setting in the Netherlands for persons with intellectual and sensory disabilities. Among the persons who live here, are persons who are congenitally deaf-blind. The dental health of persons living in institutions is often very poor. The consequences can be serious, for instance pain, difficulty with eating and drinking and a bad smell. Poor dental health care of persons with deaf-blindness can even lead to communication problems. When a person who is deaf-blind has a bad smell, it is not pleasant to stand very close to that person, which is needed to communicate. The person may also have a lot of pain, which interferes with communication. In the Netherlands a project was launched to improve dental health care of clients living in institutions and depending on caregivers. Different disciplines are working on this project, for example the dentist, doctors, and caregivers. De Brink participated in this national project with eight clients with deaf-blindness. In this presentation, I want to tell you how we implemented a dental health care plan in our group homes, to improve the dental health care of our clients. We started with a meeting with the dentist. He told us about the importance of good brushing and how to do this. It is a common fact that maintaining good dental hygiene by someone other than yourself is difficult. Some of the reasons for this are physical disabilities of the client, uncooperativeness because of the intellectual disability, not enough time for brushing the teeth by the caregivers, and lack of knowledge and skills of the caregivers. For each client we created an individual dental health care plan. This plan shows how we must brush the teeth and what is necessary to keep the mouth healthy. Since we use the dental health care plan the clients have less stress and pain, which benefits the communication.

2871 Description of the attention of the Multiple disable and deafblind population at the Panama institute of habilitation

Staff Development Effective Models and Creative Approaches

Oral presentation

Laura Esther Araba de Maldonado

Antecedents: The Education is a Human Right, for that there should not differences to offer education services for a child with the last methodologies and effective education practices. The Panama institute of habilitation is an institution that offer habilitation process to children and young adults from 60 years ago, attending since the beginning the visual impaired, hearing, cognitive challenge, cerebral palsy, autism, early intervention as well as attention disabilities, multiple disabilities and deafblindness, there were so much needs on the populations at the time. - Gap in the attention focus on their needs; - None professionals with pertinent teaching skills; - Parents no prepare to challenge the child condition; - Weakness at the methodology focus on effective practices. In 1992 we started new opportunities to improve the quality of life of multiple people and deafblind ones in our institution with the support of Hilton through Graciela Ferioli y Steve Perrault, Improving: - The attention offer to deafblind and multiple disable population; - The agreements: - Permanent training to teachers, technicians and administrative staff; - Train parents of deafblind and multiple disable; - Meetings of parents from the region; - Professionals train with University courses (2), *leadership* (1) visiting other programs (5); - Economical support for: Teachers meetings; Parents meetings; Material for the population for the region. We wish to show the following: - The achieved effects by the Professionals train in the attention of the population; - Those days they are offering services near their houses with education programs at their communities (Universal Model); - They have full time attendance with furniture's and tools for their needs; The big changes since 1992 until today; - The effects of the support by Hilton Foundation to a population of 375 children with multiple disabilities and deafblindness all over our region.

2874 The performance of professionals and families in the collaborative team for the integral development of children and youngsters with multiple disabilities, visual impairments and deafblindness.

Families Supports and Partnerships

Oral presentation

Helena Burgés Olmos, Elenir Ferreira Porto Carillo, Maria Teresa Borro

The presented communication and orientation difficulties of the families related to the routine activities of their child, inside and outside the ADEFNAV, motivated us to organize a project in which the difficulties of integration and communication could be mitigated, by focusing the importance of capacitating families of multiple disabled babies, children and youngsters (with visual impairments and deafblindness). ADEFNAV – a resource center for multiple disabilities, visual impairments and deafblindness, has proposed a project in which the starting point was the active involvement of families in the individual assistance of their children. The main goals were the following: to integrate the families in the Adefav's activities, to clarify concepts related with deafness, blindness, multiple disabilities and deafblindness, and to present ways to communicate and to emphasize the importance of "communicating". In a partnership with Perkins International and with Big Lottery – Sense, it was established a training program with 80 families and caregivers, from 2009 until 2011. This work was held given the fact that the families participated in the decisions with the collaborative team and during the development of the Individual Educational Plan (IEP) for their child, from the beginning in the Early Intervention (zero to three years) until the youngsters who are in the Specific Educational Program III, transitioning to adulthood. To achieve this, Adefav worked in accordance to the families' needs and, striving to be able to provide them with more substantial content, started a systematic service twice a month in order to capacitate the families, by offering information and clarifying issues concerning their interests. The subjects were listed according to the survey previously carried out with families, seeking to follow the guidelines of the Conference on the Rights of People with Disabilities. The information transmitted was focused on etiology, terminology, concepts related to the difficulties of their child, as well as issues related to public policies, rights and duties, including Libras lessons, alternative communication, orientation and mobility and the comprehension of the implementation of PEI. What we could observe as an outcome of this project was that after the families acquired more information and started to reflect deeper on the emotional development and on the shortcomings, they began to be more motivated to establish strong ties with their children and to stimulate them in the educational process.

2875 Deficiência Visual Cortical – Características neurológicas, avaliação funcional e intervenção para crianças com surdocegueira e outros comprometimentos

Educação/Reabilitação, abordagens inovadoras para crianças e adultos

Apresentação Oral

Marilene de Souza Silva, Ana Marcia Fernandes Chavez de Jesus

Nos últimos anos, tem sido constatada, a deficiência visual cortical em muitos casos de crianças com surdocegueira e outros comprometimentos que procuram a ADEFNAV - centro de recurso em deficiência múltipla, surdocegueira e deficiência visual. Os inúmeros questionamentos sobre esta deficiência nos levaram a buscar maiores informações sobre esta dificuldade visual. Devido aos comprometimentos associados, muitas vezes o diagnóstico exato sobre a visão fica impossibilitado. E o diagnóstico médico, nem sempre corresponde com o que a família e educadores percebem no dia a dia nas respostas das crianças. Faz-se necessário uma observação detalhada e cuidadosa para entender como a criança recebe e responde as informações visuais. O objetivo geral deste trabalho é discutir as conseqüências da deficiência visual cortical, apresentar estratégias de avaliar funcionalmente a visão, estratégias de intervenção e de estimulação visual que possibilitem a aprendizagem de crianças com deficiência visual cortical. Para que possam desenvolver suas habilidades visuais. Em comparação com o sistema somatossensório e auditivo, o sistema visual está relativamente imaturo ao nascimento. As crianças pequenas, não percebem detalhes e contrastes, porém conseguem perceber cores e movimentos. A capacidade do funcionamento visual depende de desenvolvimento - quanto mais a criança olha, mais estimula os canais cerebrais. Na deficiência visual cortical as funções visuais não apresentam nenhuma alteração, porém o córtex visual não consegue muitas vezes, processar as informações recebidas. Isto é uma circunstância que indica que os sistemas visuais do cérebro não compreendem e não interpretam o que os olhos vêem. Faz-se necessário recorrer ao protocolo de avaliação funcional da visão desenvolvido pela ADEFNAV - Centro de recursos em deficiência múltipla, surdocegueira e deficiência visual - onde se observa o comportamento visual e identifica como a criança está usando sua visão, seu campo visual, sua preferência de cores, luminosidade do ambiente, bem como a distância e tamanho de como a criança responde aos estímulos visuais. Os dados coletados durante a avaliação funcional visual serão utilizados para elaborar o plano de intervenção de acordo com as necessidades específicas da criança, favorecendo desta maneira o seu desenvolvimento visual dentro de atividades diárias e principalmente para oferecer oportunidades para o uso funcional da visão.

PALAVRAS CHAVES: Deficiência visual cortical, estimulação visual, avaliação funcional da visão.

2875 Cortical Visual Impairment – Neurological Characteristics, Functional Assessment and Educacional Intervention for Children with Deafblindness and other Impediment Education/Rehabilitation, innovative approaches for children and adults

Oral presentation

Marilene Souza Silva, Ana Marcia Fernandes Chavez

In recent years, has been found, cortical visual impairment in many cases of children with deafblindness and other disabilities who seek ADEFNAV - resource center on multiple disabilities, visual impairments and deafblindness. The numerous questions about this deficiency led us to seek more information about this visual impairment. Due to commitments associated often accurate diagnosis of vision is impossible. And the medical diagnosis does not always correspond with the family and educators realize on a daily basis in children's responses. It is necessary a detailed and careful observation to understand how the child receives and responds to visual information. The goal of this paper is to discuss the consequences of cortical visual impairment, strategies of functional assessment, strategies for intervention and visual stimulation to enable the learning of children with cortical visual impairment. So they can develop their visual skills. Compared to the somatosensory and auditory system, visual system is relatively immature at birth. Small children do not notice details and contrasts, but can perceive colors and movements. The capacity of visual functioning depends on development - the more the child looks more channels stimulates the brain. Cortical visual impairment in visual functions do not show any changes, but the visual cortex cannot often, process the information received. This is a circumstance that indicates that the visual systems of the brain do not understand and interpret what the eyes see. It's necessary to use functional visual assessment developed by ADEFNAV where we see the visual behavior and identifies how the child is using his vision, his visual field, your choice color, ambient lighting, as well as distance and size as the child responds to visual stimuli. The data collected during the functional visual assessment will be used to develop the intervention plan according to the specific needs of the child, thus favoring its development vision in daily activities and especially to provide opportunities for functional use of vision. **KEY WORDS:** cortical visual impairment, visual stimulation, functional assessment of vision.

2876 A FAMILY LEARN FROM THE DAILY PRACTICE ACTIVITIES OF A DEAFBLIND TEENAGER

Families Supports and Partnerships

Oral presentation

Rita de Cassia Silveira Cambruzz, Maria da Piedade Resende da Costa

The goal of this research is to present the attention strategies used by a mother with a teenager, then they could identify and analyze the elements used for the positive attitude on new learning actions and to keep the attitude to the established ones. During the research we offer support to the mother through explanations such as how to deal with the teenager during the task, the developments of activities were in natural environments. We used a sign language book with the mother teaching both of them the activity signs, objects of reference, looking to expand those in the learning action. We observed the relationship between both in the activities development. The results shows than the learning process by the mother has being effective, because the young is learning the activity, however she requires adjustments to do the activity without remembering her time to time.

2881 COLLABORATIVE APPROACH FOR THE EARLY INTERVENTION WITH INFANTS WHO ARE DEAFBLIND AND OTHER COMMITMENTS

MODELS OF PROGRAMS, SUGGESTIONS FOR IMPROVEMENT OF SERVICES

Marilene de Souza Silva, Natallie Carmo Prado

The goal of this paper is to present a model of early intervention conducted in ADEFNAV - Resource center in multiple disabilities, visual impairments and deafblindness. The sessions are done in groups, with the baby and its mother/caregiver. With collaborative team that develops an individualized program geared towards the needs of each baby. This program includes: direct interaction with the baby, home visits, family support group (counseling, specific professional guidance), training facilitators, group of infants with family, individual therapy - physiotherapy, occupational therapy, speech therapy, stimulation and visual rehabilitation. Babies with deafblindness belong to a group with ongoing needs, which may change or vary depending on the age of onset of disability, the degree of sensory loss, the joint presence of other disabilities, the conditions of the environment they live in and early intervention . These babies will have difficulty learning through observation or independent exploration. They are often unable to learn to identify the result of his action during everyday experiences. The child with deafblindness loses a lot of information that are essential to their learning, and learning that incidentally, is very limited. Either way, they cannot learn what they cannot detect ,or understand what they are missing. They have difficulties to access enough information to understand what is happening around you. And this may result in confusion and frustration and, in most cases, isolation or aggressive behavior. Moreover, the lack of access to auditory and visual information causes extreme difficulty in all areas of development, because they are deprived of connecting with the world and, consequently, learning, communication, and social and emotional development are also affected . These children need early intervention so that their development is as effective as possible. They also need appropriate stimulation for them to learn to use their remaining senses, thus beginning an interaction with the environment, facilitating the future process of educational inclusion. **KEY WORDS:** Early Intervention Collaborative Team, Deafblind.

2882 Partners in communication

Staff Development Effective Models and Creative Approaches

Oral Presentation

Isabel Amaral, Alice Rizo, Eva Camacho, Cristina Bravo, Ana Varge

Communication with students with severe and complex disabilities requires communication partners who are able to adapt their communication style to the needs of their students. Not everybody involved in an activity is a good communication partner for a student with severe and complex disabilities. Communication partners for such students are usually chosen because either they have a major role in the activity and/or they have a major role in intervention with the student. In both cases partners are expected to identify, respond and interpret students' behaviors, to be able to pace interactions according to the student's needs, to use communication forms which are adequate to the student's needs and use a conversational approach as a basis for communication. In this presentation we discuss results of a research project aimed at describing and analyzing communication competencies for professionals working with student with severe and complex disabilities. Competencies, for the purpose of this project, were considered as the result of combinations of knowledge, skills and attitude. Six studies were carried out. The first three studies aimed at describing communication competency for professionals working with students with severe and complex disabilities. The last three studies analyzed interactions between teachers and students. Results of these studies indicate that communication is viewed as a need but not identified as a skill to develop. It also shows that basic communication rules are frequently violated for lack of appropriate information on how to properly interact with these students. The discussion of project's results stresses the growing need for specific training programs which include developing communication skills for professionals to increase quality communication with their students with severe and complex disabilities, and to allow for communication interactions which mediate learning in an effective way. Some practical suggestions for training are also included which result from a reflection over project results and aim at increasing communication competencies.

2883 A piece of the puzzle to understand tactile linguality

Education/Rehabilitation Innovative Approaches for Children and Adults

Oral presentation

Kari Schjoll Brede

Over the past few years the subject of tactile linguality has been a focus of multiple Nordic researchers, with several projects with different perspectives running. One of the main questions asked is: We have seen that there often is a gap between what we perceive to be the cognitive capacity of some persons with congenitally deafblindness (CDB), and what we can see them expressing linguistically. What is the reason for this? Why do the communication skills in children with CDB some times develop slower than expected? In ordinary children, the communication development happens "by itself" through natural imitations and more or less systematic repetitions and variations of a cultural language. The microscopic details on how the first expressions are formed and filled with meaning are not well documented. In persons with CDB requiring tactile communication this process does not happen easily, one of the reasons being that a natural tactile language does not exist. As a communication partner we need to know more about how to interact tactilely and lingual with the congenital deafblind person. We know that dialogicality is important to this development, along with reciprocity and joint attention. The importance of sensory access to the world and to the communication is another aspect. There are several details we know too little about, and we believe there are some processes we do not know at all. In the Viataal booklets on Communication and Deafblindness we can find examples and descriptions of different kinds of gestures, proto signs and signs and their origin. Those examples coincide with the findings in the masterthesis "Let me join your attention" (Brede 2008). In the case study we can follow how a sign is created through a blend of interior and exterior sensory impressions, through interaction with a skilled partner: from a gesture grown out of a BET (body emotional trace) to a shared and negotiated sign. By following this gesture over time, there was another interesting finding: stage-by-stage the tactile togetherness grew into advanced forms of joint attention. This presentation illustrates, with help of video and images, some of the microscopic details on how the first expressions are formed and filled with meaning in the communicative interaction between a congenitally deafblind boy and his teacher. It represents a small contribution to the questions presented above. It is one small piece of the puzzle of finding a natural deafblind way of achieving a tactile linguality.

2886 Service Development in Mexico

Program Models Suggestions for Improvement of Service Delivery

Oral Presentation

Marta Elena Ramírez Moguel

In Mexico on 2006 started a process to improve the quality of education at the services for students with multi disabilities including those with deafblindness and their families offer by the Secretaría de Educación Pública (SEP) in coalition with private organizations like Centro de Rehabilitación e Integración Para Invidentes (CHIPI I.A.P.) and Asociación Mexicana Anne Sullivan (ASOMAS I.A.P.) in collaboration with consultants and with the support of Perkins International. This process started with a research that focus on locate the population at national level and after that a plan of action with responsible of special education of country was developed in order to improve the quality of services that was offered. Some of the actions that were considered can be mentioned: teachers, administrators and parents trainings. For these trainings were implemented different strategies of staff development: courses, on line courses replicated in Bolivia, Colombia and Peru, workshops, site visits, program visits. Also, several support materials like videos, booklet were developed with the objective to considerer the ecological vality. The strategies mentioned below were adjustment to the straight and weakness detected through a quality Indicator Services Chart. These activities also alowed: *at educational level: to make more visible the population with multi dissabilities including those with deafblindness; increase the number of students who are receiving services; improve the teaching practice of the teachers; *at family level: empowerment the parent role in the education process; and at government level: new coalition with other department was established like Secretaría de Educación Especial del Distrito Federal. The content described below will be supported by videos showing the process developed in Mexico.

2888 Family involvement: multiple actions in educational services to the deafblind and /or with multiple sensory impairment.

Apoio familiar e parcerias

Apresentação oral

Jacqueline Ricartes Costa, Naya de Arruda Torrezan de Souza

The educational service to the child or young person with deafblindness and / or with multiple sensory impairment, also including cases of children with serious illnesses or syndromes, has a general objective of the acquisition of independent living skills. When an interdisciplinary team of a specialized educational institution is open to have different moments of exchange among professional, for example, study groups, collective planning and study cases, possibilities to extend participation and family involvement also multiplied. During these different situations, staff dialogues with each other using speech inherent in their areas of actions where each professional determines and scales directly their actions, but also where the interdisciplinary team as a whole, structures new possibilities for monitoring the case and, therefore, involve the family, innovating the list of actions proposed and commonly found along the same. Thus, the well-known educational meetings with the group of parents - which Group Dynamics are applied, the guidelines specific to the family - guaranteed places and times reserved, or even home visits, widen for the execution of other procedures and ways of monitoring the case, for example, the support of a professional staff at the systematic medical consultations, or follow-up visits to complementary actions that occur outside the institution, such as Horseback riding and hydrotherapy, plus the possibility to structure a study group with parents and / or immediate family and involved with the case. In this sense, the development of a program of individualized care for these severe cases and intensive and continuous support, based on a functional curriculum, can promote a work that addresses the specific needs of children and educational priorities established by the family. Expanding the contexts of effective contacts and exchanges between school and family, the chances of generating creative alternatives increase in the process of educational services the child / young adult deafblind and / or multi-sensory impaired, speeding some results from long to medium term.

2889 Inclusion foundations: three research projects focused on sensory disabilities

Research Scientific and Evidence-Based

Apresentação oral

Saulo Cesar Paulino e Silva, Elcie F. Salzano Masini, Isabel Amaral, Maria Aparecida Cormedi, Maria Cecilia de Moura, Shirley Rodrigues Maia, Tanya Cecilia Bottas de Oliveira e Souza

1^o.st This research registered the questions or doubts that caused mothers or caretakers of children with multiple sensorial deficiency to seek help of for health professionals or education professionals; it also registered the places (clinics or institutions) where they sought information, explanations or counseling for the assistance of their children; it also inventoried the counsels received by the mothers and the kind of assistance the children received; at last it systematized the human and material resources that contributed for the development and education of the children with multiple deficiency. The investigation aimed to get information from birth to the date of the registration of deployments. Subjects of the research: 10 mothers of São Paulo city – Brasil; 10 mothers of Lisbon - Portugal; 05 medicine doctors of São Paulo city and 05 medicine doctors of of Lisbon; 05 teachers of São Paulo city and 05 teachers of Lisbon. Method: Analysis of the individual interviews of the subjects of the research. Simplified results of that analysis: Brasil: 1) Mothers: learned alone and never felt oriented or helped; the support was from the own family and friends; the assistances that helped were, usually, from specialized institutions; 2) Professionals: confirmed that mothers had not been listened on their solicitations. Portugal: showed more satisfactory assistance. 2nd Registered conceptions of "not-hearing" and "not-seeing", and the ideas of "the importance of those senses to learn", from students in the last year of Pedagogy, Phonoaudiology and Psychology of public universities of four Brazilian States, and of the city of Setubal - Portugal. It aimed to verify if the idea of the students about the importance those deficiencies to learn, was equal or different when the deficiency was congenital or acquired; it aimed also to verify if those courses offered information about being-deaf and being-blind and the specificities of perception and cognition of deaf and blind people; it compared the data of students of the each of the three courses, concerning the general goal and the specifics goals. Subjects of research: 109 students of Pedagogy; 86 students of Phonoaudiology; 82 students of Psychology. Method: Analysis of the answers to the question of choosing between to lose sight or to lose hearing; and between to be born either with vision or with hearing; analysis of the answers to questionnaires about deaf persons, persons with visual deficiency, and about their learning. Simplified results of that analysis: 1) the results of the students of the three courses of the five universities presented few differences, confirming the student's poor knowledge about specificities of perception, thought and language of people with sensorial deficiencies; 2) the education of those professionals is not preparing them to become the foundations of social and educational inclusion of people with deafness or hearing deficiency and of people with blindness or visual deficiency. 3rd The foundations to inclusion in the daily living of the community. In development 2011 - 2015

2935 What is this thing called CHARGE? An Overview of CHARGE syndrome

Program Models Suggestions for Improvement of Service Delivery

Oral presentation

Pamela Ryan

This session will provide an overview of latest diagnostic and medical information on Charge Syndrome and provide a forum for participants to discuss outreach and identification issues in their home countries. CHARGE syndrome is a genetic disorder that is characterized by a variety of medical, physical, sensory, and developmental issues that until fairly recently, were described by its acronym C-H-A-R-G-E. This acronym describes a set of features seen in many of the children. The letters stand for: Coloboma (of the eye), Heart defects, Atresia of the choanae, Retardation of growth and/or development, Genital and/or urinary abnormalities, and Ear abnormalities and deafness. CHARGE syndromes now fairly well recognized pattern of birth defects occurs in approximately one in every 9 to 10,000 births worldwide. The discovery of the gene for CHARGE syndrome in 2005 has made genetic diagnosis possible, but it remains expensive and imperfect with only about 2/3 of people testing positive for the gene. Thus, clinical (descriptive) diagnosis remains in place but with a change: identifying a positive CHARGE syndrome diagnosis by clinical definition is now done by identifying "major" and "minor" features. For example, a positive clinical diagnosis, done by a qualified medical geneticist, would identify 4 major features specific to CHARGE: Coloboma of the eye, Choanal atresia or stenosis, cranial nerve abnormalities, and the CHARGE ear. Identifying 3 major and 3 minor characteristics could also make a positive clinical diagnosis. Minor characteristics are features common to CHARGE, but also identified in other conditions as well (i.e., heart defects, cleft lip/palate, kidney abnormalities) so they alone would not determine a positive diagnosis for CHARGE syndrome. These children are very complicated and come with a long list of "care and maintenance" instructions. Their complex combinations of vision, hearing, sensory, medical, cognitive, developmental, and behavioral issues lead to significantly different growing and learning issues that can seem daunting in their early years. However, given the proper time and attention to details, it is amazing to see the accomplishments of this remarkable and interesting group of people.

2938 Education on line: a contribution to education accessibility in Latin America

Staff Development Effective Models and Creative Approaches

Oral presentation

Elizabeth Camacho Hernandez

Globalization as a world economical system has achieved our countries, for that reason we have to build new strategies to train trainers, families that fund a barriers such as time and family sacrificed to assume the economical responsibilities to attend the technical or university training to be able to cover the disabled people needs. The online education in Latin America is providing a low cost opportunity to break the distance barrier, the timetable for teachers, parents, tutors and professionals that act as intervenors. The online education offers the possibility of designing with different information management levels depending of the population needs, respecting their language, culture, habits to bring more opportunities for the intervenors that interact with diverse needs and capacities population, such as deafblind and multiple disabled ones. The online education is a good example of a strategy that allows us to improve the equality of opportunity and quality of life for the trainers, families and disabled people. The people that access to the online training designed in natural language and use by TICS (communication information technology) or people that are unlettered that has a multiple disabled or deafblind community or family member could access to information to be part of the education using demonstrative videos. New technology let the online education go forward, taking the place of what called distance training through internet, communication information technology and learning virtual environment are big and offer training facilities all the time. This online training had to be management by different entities as education ministries, universities with courses design for that, technical centers, school centers, resource centers that done transitions in the attention to train more inclusive human resources.

2939 Rubella síndrome in Argentina

Research Scientific and Evidence-Based

Oral Presentation

Nora Beatriz Sinopoli, Aurea Maria Soza

Data based on the clinical diagnosis of rubella in our country show a cyclical pattern of incidence, with peaks every 5 years or so. The highest record was in 1997, exceeding the 50,000 cases. In 1998 Argentina joined the MMR vaccine (MMR) to the National Calendar for 1 year olds, with a booster at school entry. Have also been carried out follow-up campaigns to provide a second opportunity for measles for children aged 1 to 4 years and ensure that no subject in that age cohort. From these actions, there has been a significant decrease in reported cases of rubella, especially in children, target group for vaccination. It is estimated that an epidemic year, 1050 cases of SRC are produced in a year and in a no-epidemic year, 105 cases of the syndrome. Therefore, it is expected that in 10 years 1995 cases of CRS occur in Argentina. This figure is calculated from studies of probability of occurrence of congenital rubella syndrome (CRS) and considering that the latest outbreak of rubella in our country occurred in 1998. The estimated cost of lifetime treatment of a child with CRS, is approximately \$ 180,000, representing approximately \$ 359,100,000 for the estimated cases in 10 years. The operational cost per person vaccinated is \$ 4.50 and \$ 30,633,188 the total cost of the campaign, what it means for the health system an estimated \$ 328,436,812 profit. The main justification for the accelerated vaccination strategy is to reduce the time it takes to interrupt the circulation of rubella virus and eliminate the SRC. In 2006, the National Campaign starts having vaccinated only women between 15 and 39 years, achieving 99% coverage. By December 2008 we obtained a 90% coverage of a campaign only to men between 16-39 years. Since June 2009, Argentina is implementing supplemental immunization campaign for men to obtain coverage above 95%. As for the family and social impact of people with CRS we may include a family experience which states that the lack of specific services in the areas of health and education, it demands the family a huge emotional and financial stress, leading to the need of creating special schools and think of future residences for their children. In regard to health is still an outstanding debt, finding doctors who can watch the late manifestations of CRS. While the country has not conducted investigations of such effects, should be aware that as technology develops methods for medicine, the survival of people with SRC is higher, and is accompanied by expressions such as diabetes, arthritis, behavior disorders, neurological disorders, among others, as documented in research conducted in United States.

2940 Public policies related to the social and education inclusion of deafblind people
Program Models Suggestions for Improvement of Service Delivery / Inclusive Education
Oral presentation

Alicia Bonetto

In Cordoba, Argentina the education ministry is in charge of special education. This special education adheres to the policies that are part of the new education law which focuses on inclusion, quality of education and equality for all. Those schools that work as “special education settings” perform two type of functions. One function is undertake early diagnostics of the disable children to supporting their education program. The second function is to work as a resource centre. In the beginning, the Perkins International program supported a limited number of education places for these disabled children in the public system. Now they support more schools offering support and advice to promote their inclusion in the community school. Currently we have 400 students with deafblindness and multiple disabilities in the mainstream education system. These individuals comprise 10% of the students enrolled in special education programs. This situation that the deafblind and multiple disable students are being provided inclusion opportunities is the result that teachers have received the training.

2941 Communication needs and others that came from deafblindness cover through the telephone?

Education/Rehabilitation Innovative Approaches for Children and Adults

Presentation oral

Eugenio Romero Rey

Experience has shown us that another form of technology that can contribute to the communication needs of deafblind people is the use of text messaging or “sms” using mobile telephones. Thanks to the techniques used with people who are blind, it is possible for deafblind people to use mobile phones. A deafblind person with some residual vision or hearing can send text messages in Braille, by accessing the voice function and using visual adaptations for the telephone screen. This possibility availability for deafblind people is thanks to 3G technology. I wish to compliment Apple’s contribution for its iOS operating system and the iPhone terminal. Applications such as “dragon dictation” and “where I am” (GPS) allows a deafblind person to access Braille. Together, these systems offer the same communication tools to people who are deafblind that hearing and seeing people benefit from.

3094 Public-Private Alliances for the education inclusion of children with visual impairment, deafblindness and multiple disable on the existing education programs

Modelos de Programa sugerencias para mejorar los servicios ofrecidos

Poster

Luz Helena Tirado, Marcela Quiroga Giraldo.

Bogota as the Colombian capital is a complex city, with diverse social conditions such as poverty, displacement, violence. In the last 10 years we did so many efforts for the children and young ones in the law number 1098 at the infant and adolescent code on disabilities and social inclusion, specially the last 4 years. In this framework Ideas day by day foundation on years 2007-2010 assessed 25000 children from 0 to 6 years old to research as an early intervention for disabilities and development problems, establishing links with national and international, private and public organizations. Designed with the Multiimpedidos foundation in the city of Medellin a project that let us participate in the project called "wider opportunities for visual impairment, deafblindness and multiple disable" and "CBR social participation strategy in Bogota, thanks to the support of INGOs as Perkins- Sense International and CBM Christoffel-Blindenmission. It is based on the training of local community agents, strengthening families and professionals in the attention of disability children on a ecological-functional focus. Professionals develop actions to train the local agencies and some that will train others to attend them (inside each place and with specific role for the collaborative work) through conferences, speakers, workshops, practical actions, institution visits, home visits, company the health visits, curricular changes and easy adaptations. This process was focus to 95% of the population that were public workers and 5% private ones. We train 20 professionals for the inclusion and implementation of the CBR leaders In the city as a complement of the education programs, 55 professionals are part of the training workshops and 300 come to the awareness and general information. This project is develop in 5 cities and look to join a private and public alliances and the expert advise of the centres such as REI at Cartagena city, FUNDAVE in Barranquilla city, FULIM in Cali city, Multiimpedidos in Medellín city and Ideas in Bogotá, to support the inclusion on mainstream programs in the rural and urban areas of visual impairment, deafblindness and multiple disable children and Young

3095 Family Change capacity to create an inclusive context

Family, support and alliances

Oral Presentation

Luz Elena Tirado Betancur

Traditionally the professionals are in charge of the disable children education at different special education settings. They consider that parents have a secondary role, even knowing that the parents are the first teachers, no one know better the child than them and no one has more interest in him or her good orientation. Now days those ways of thinking and acting had been changed, because it has been analyze by studies the intervention factors on the relationship and the interaction between the parents, the families and professionals of disable people. The parents' empowerment let open opportunities for those to participate in the development of each family member and at the integration and inclusion of them in the society. The parents' drama is the expected perfect child that did not arrive. The expectative they had before the child born are fronted, stimulated, judged, criticize, hated, loved, encourage because what happened was not expected. With the "Experience education" strategy management by the Aventura project through activities we bring success or analysis and forgiven for the fail or the mistakes in the activity action done. The actions at the meetings shown problems for the parents in group or individually following the steps: difficulties evaluation, to look for a solution alternative, to choose the best and look for strategies to solve it and a live training, through the internalization- reflexion – action. To improve the self concept and self steam. The parents meetings looks for them to be able to show the mean ability to transfer the help intention, establish mutual trust measure for the partners and self information. The success and the fail are not important in those activities but the join is, because let the participants to have more trust in themselves, when they are in front of others to take decisions and acceptance the live challenges. A collaborations and support atmosphere motivate the participation and the trust in the group members because involve the physical and verbal interaction. This way brings the security conciseness in themselves and in others. The activities are fun. For that reason the laugh is a therapy that release the stress and the sadness and is an essential part of the process, add to the love component and the respect that let them integrate in the personal life and the socially with a better quality of life for the family.

3097 Curricular Alignment; Development Curricular Proposal based on the Functional Ecologic perspective: implementation and experiences in private and public schools

Personal development /training effective and creative models

Poster

Karina Medina, Graciela Ferioli, Maria Aparecida Cormedi

The UN Convention of the rights of disable people proposal said to promote, protect and ensure to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. On those concepts are include the rights and needs of disable people whom could be congenital or acquire people who have limited access to the information by the hearing, visual, physical and/or cognitive limitations. This condition affect the concept acquires, the person development and depending on when the disabilities appear, the grade of it and the possibilities that the environment offer to him or her. On the rights and needs of multiple disable people we want to underline the education services that should respond to the proposal mentioned. In our experience we had seen that the models where the professionals are the ones that assess and work with the students in an isolated way. As a consequence they have difficulties to reflect the program development, the priority students needs and his or her family and the environment in which he or she belongs to” Ferioli, G. (2003). From this doubt and taking in account the families, professionals and multiple disable children and young needs that are part of the education process is that some private and public education institutions in Cordoba, Argentina for multiple disable children and young, to improve their quality of life, for the students to develop all the abilities and potentialities started a training process to let analyze and improve the education proposal, the teachers work and the implementation of them at the development curricular based on a ecological and functional perspective. This process was done with the advice, based on the experience, concepts and theory we got a document on “Curricular alignment” that we consider will be a guide for other education services. On this presentation we want to share the theory tools, the design and implementation of the curricular proposal for our institution on the educative system.

3103 Inclusion as a Continuum for Students Who Are Deafblind

Program Models Suggestions for Improvement of Service Delivery

Poster

Gloria Rodriguez-Gil

Stemming from the presenters multiple experiences with students who are deaf-blind, their families and educational teams in many diverse educational settings, this workshop will discuss visions, roles, attitudes and contexts that have demonstrated effectiveness in the improvement of inclusion for students who are deaf-blind. The presentation will explore the benefits of a continuous view of inclusion, not as a discrete set of absolute categories but as a flexible, multiple and malleable set of ranges that can be understood and used by the educational teams to improve not only the interaction of the students with their immediate environments but also applied to improve the quality of their life experience in many simultaneous areas. The workshop will also look at the students profile as it will influence in unique ways the educational setting. Students who are deaf-blind are very diverse, so their strengths and needs are unique to each student, and in consequence it is critical for the educational team to know the students individual characteristics. This presentation will go through the information about the student that may be necessary to have in order to better support the student in a greater inclusive setting. Finally, students who are deaf-blind need technology to compensate for the lack of access. This presentation will review some of the technology, from simple to specialized. This technology may support the student to better access, learn and interact with the environment. The central concept is that the student is a complex entity moving in a complex setting, in which certain characteristics will be more or less developed and more or less suited for the completion of fundamental tasks, and that by not taking an absolute approach and recognizing the diversity of manifestation of the student, progress in inclusion can be achieved by the nurturing of the strengths and abilities in the diverse contexts where these characteristics are present, regardless of the sophistication of the educational setting. To this effect, this presentation will provide specific examples and experiences with the hope that the participants will extrapolate to their own context and increase the ranges of inclusion possible to the students in their care.