

W1.

Talk with me the way I do! Early dialogues of a congenital deafblind girl with Cochlea Implant and her interventioner

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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", which is based on the project "dialogic development of infants" by Prof. Dr. 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

In the dissertation, parents and their deafblind children up to and including the age of six are monthly video taped in their natural setting for one year during an aimless interaction such as playing with or without an object. The first four minutes of the data are analysed with computer software - especially for observing behaviour - called Interact by Mangold. Afterwards quantitative and qualitative analyses are made.

Key results

The results which are presented refer to one pair of the 25 participants 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. The interventioner empathizes not only possible ways to get into the dialogue, but moreover the mood of the child, so that a symmetric dialogue can occur.

Main conclusions

The child shows the interventioner which ways can be used to get into a symmetric dialogue with each other and the interventioner has to listen very carefully to the offers of the child to get a hint who's turn is next: Altogether, following the child as one strategy for successful early intervention is described and outlined via video examples.

W2.

Possibilities and limits of Augmentative and Alternative Communication ACC with deafblind multiple impaired people

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Wien, Austria

As an introduction into the topic, the basic principles of human communication such as the reciprocity, the meaning of communication situations, the impossibility to not-communicate, the interdependency of transmitter and receiver within a communication process shall be briefly addressed and explained.

The following part will be discussing the theoretical basis of ACC. It will be explained how an individual multimodal communication system can be developed. Furthermore the numerous factors of influence affecting such a system will be pointed out and also show the building blocks available.

The main task in the area of ACC is to compile together with the relevant person an *individual multimodal communication system*, which is composed of the mentioned components and the communication repertoire. The communication repertoire contains the total spectrum of the individual possibilities of expression, meaning the vocabulary and their forms of representation and their codes of practice.

The possibilities and chances of ACC will be demonstrated by means of a case study and the accuracy needed to design individual multimodal communication systems.

Based on the question, how can a person communicate what and with whom in which situations so that the person understands and is understood, it will be explained how a needs - resource- and ability-orientated assessment can be performed in daily life.

Apart from facilitating different means of expression it is just as important to offer communicational abilities to the relevant person. That means strategies allowing the person to use the components of its alternative communication system in a preferably optimal way in order to make the active participation in processes of communication easier, to improve the own abilities of communication and the processes of communication.

This is the main statement of this workshop, because the transmitting of techniques of communication only is mostly not enough. It requires fundamental and the most different communication strategies in order to allow a successful interaction and dialogue.

W3

CHARGE syndrome in Italy

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CHARGE is the nonrandom association of coloboma, heart anomalies, choanal atresia, retardation of growth and development, and genital and ear anomalies. Our clinic, in collaboration with the Rehabilitation Centre of the non-profit Lega del Filo d'Oro in Osimo (Marche region), takes care of 35 patients with CHARGE syndrome. All patients are treated according to protocols to facilitate collection of homogenous data. Each patient receives specific blood tests (biochemical measurements, particularly renal function, sexual and growth hormone levels), measurement of visual acuity, audiometry and auditory brainstem response, study of IQ, echocardiogram, skeletal survey, feeding assessments (barium swallow, reflux scan), abdominal ultrasound, head CT and/or MRI scans, including imaging of the temporal bones. More recently, DNA testing for the *CHD7*, encoding the chromodomain helicase DNA binding protein, has been offered to patients with CHARGE to facilitate genetic counseling and to define genotype-phenotype correlation. Our CHARGE patients in Italy have ocular coloboma (100%); choanal atresia or stenosis (54%); cranial nerve dysfunction resulting in hyposomia/ anosmia, facial palsy, impaired hearing, and/or swallowing problems (90%); abnormal outer ears (100%), ossicular malformations, Mondini defect of the cochlea, and absent or hypoplastic semicircular canals (some evaluated cases); hypogenitalism (30%); developmental and language delay (90%); cardiovascular malformations (40%); growth deficiency (1%); orofacial clefts and tracheoesophageal fistula (20%). Molecular analysis is in progress. In conclusion, this study shows the prevalence and nature of clinical manifestations in 35 Italian patients with CHARGE syndrome. The availability of molecular data will allow correlation of *CHD7* mutations with specific anomalies.

W4

Recommended Practices for Assessing Communication and Learning Skills in Young Children Who are Deafblind

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Content. Results of a 5-year study on recommended practices for assessing communication/learning skills in young children (ages 2-8 years) who are deafblind.

Description. The challenges of assessing young children who are deafblind and who may have additional disabilities will be described. Data on attitudes and recommendations of professionals and family members regarding the assessment process will be summarized. An authentic approach to assessment for young children who are deafblind will be presented.

Purpose. In early childhood special education, high quality assessments are essential for developing intervention goals, obtaining needed services, planning interventions, and monitoring a child's progress. Communication—the ability to convey information to others and the ability to receive and interpret information from others—is fundamental to learning. Educational progress, acceptance by peers, and meaningful participation in the home and community all require the ability to communicate effectively. Many deafblind children are nonspeaking and use alternative means of communication. Assessing their communication skills is a challenging and complex process. Standardized tests administered in unfamiliar situations are unlikely to be helpful, whereas an authentic assessment approach is likely to provide useful information. The purpose of this presentation is to summarize evidence-based and recommended practices for assessing young deafblind children and to report qualitative data obtained from family members and professionals who serve these children. Specific considerations and suggestions for conducting authentic assessments of young deafblind children will be discussed.

Questions

- What are the challenges experienced by family members and professionals related to the assessment of young deafblind children?
- What assessment instruments are recommended by professionals and parents?
- What are the components of a high-quality assessment process for children who are deafblind?
- What is the process for linking assessment findings to intervention strategies and goals?

W.5

“Lost” in transition – Design and adaptation of the context to facilitate independent living all life long

S. von Prondzinski, P. Ceccarani Patrizia, E. Storani
Lega del Filo d’Oro ONLUS, Osimo (AN) - Italy

Brief statement of the content:

The report highlights the importance and methods of planning, adapting and controlling environments and furnishings before, during and after the delicate transitions that the deafblind and multisensory impaired go through during their lives.

Description of the presentation:

Every important change in the context in which a deafblind or multisensory impaired person lives, learns or works may cause problems of orientation, mobility and independent and may make it necessary to begin and continue a process of planning the environment and furnishings in a way which reduces barriers and increases ease of use. Identification and recording of needs and forecasting future needs as well as transferring knowledge and offering support during change are essential elements in the planning process. The presentation illustrates the evolution and configuration of such a process at the Lega del Filo d’Oro. This association helps deafblind and multisensory impaired people at several special centres and at home, school and work. The planning process is carried out by a multi-professional staff which uses different operational tools, such as charts, databases, specific multimedia archives, and is supported by the Documentation Centre. The planning process takes account of the ICF concept of inter-relationship between personal factors and the context.

Summary of the main purpose of the presentation:

The presentation offers a method for planning, adapting and controlling the environments and furnishings which are present for the disabled person at different transitional phases.

Questions that will be offered for discussion in the presentation:

Are general or personalised solutions better?

How can a participative planning process be encouraged?

W6

Deafblind education and vocational training in Sweden

H. Sikh, I. Sandelius, A. Mollberg, H. Brink

Upper Secondary National School for the Deaf and the Hard of Hearing, Örebro, Sweden

Subject heading:

Deaf-blind children and the schooling situation for young people in Sweden

Contents overview:

Background facts:

Overview of Swedish school system and Swedish constitution

Unitary school system

Population

Globally unique tradition of national registration and population statistics

Presentation of *Riksgymnasierna* (national high schools) for the deaf and hard of hearing at Örebro

High schools for the deaf, hard of hearing, deaf-blind and speech-impaired.

School, accommodation, leisure.

Unique assignment direct from the department to Örebro district council.

Only in Örebro

Selection. Finances

Deaf-blindness policy

Nordic definition

Populations. Population changes.

Deaf-blind from birth. Deaf-blind later onset. Diagnoses.

Where are the children/young people?

School career, future??

How do we work among pupils?

Pedagogics, methodology, communication tools

Work partners

Holistic view

Unique basis for study/research?

Vocational training.

Future jobalternativ

W7

Basal Theatre (based on Basic Stimulation®) – a project that shows the possibilities for development advancement of deafblind children and youth

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Deutsches Taubblindenwerk gGmbH, Hannover, Germany

Content. Our presentation describes Basal Theatre, performed by deafblind pupils with profound and multiple disabilities.

Description. We will start with background information about the project and our understanding of Basal Theatre. After that, a theatrical situation or performance will be described and shown. This is followed by a resulting situation: A teacher communicates with a pupil, referring to the theatrical situation.

In conclusion we will show some perspectives for the project and the development potential of the pupils.

With the aid of video examples we want to create an accessible lecture for the audience.

Purpose. Since five years our school is providing a theatre project for our pupils. But only the higher achieving pupils were able to participate. The idea for our project bases upon the wish to provide a theatre project for the lower achieving pupils.

The outcome of this was our concept for Basal Theatre for Deafblind Pupils. The background of this concept is our knowledge of Basic Stimulation and Mrs. Pollicinos conceptual skills of Eurythmic education.

Questions

- Could such a project be possible in your school?
- How could it be modified?
- Performing theatre with children with profound and multiple disabilities: How much understanding is essential?
- Could you think of further possibilities according to the project to improve communication with deafblind pupils?

W8

Early intervention in sensorially multidisabled children: the Robert Hollman Foundation experience

P. Cadironi, J. Lanners, R. Salvo, G. Bartoli, E. Mercuriali, M. Soni

Robert Hollman Foundation, Padova-Cannero Riviera (VB), Italy

At the Robert Hollman Foundation – centre for counselling and supporting the development of sensorially multidisabled children - we focus particularly on the support of the family. In this work we present a service offered by our Foundation to babies (0 to 18 months) and their parents.

Parents struggle to “meet” their deaf-blind child and often have to pass him too soon onto professionals, missing out the possibility to attune and to create an initial bond.

The threat of developing psychopathological defences and psychic withdrawn is always present in these children because of difficulties in perceiving and coding the reality. They are more at risk when the relationship with their love objects becomes difficult to be established.

To promote a healthy mental development in sensorially multidisabled children we have created a model of support and guidance for the family to prevent disturbances in the parent-child relationship and within the child development.

After a baby is observed by a multiprofessional team to create a profile of his development and medical problems, baby and parents are welcomed by a smaller team (psychologist and motor-vision therapist) that works at different levels:

- enhancing maturation (when relational problems seem to disturb the sound development of the child),
- creating a bridge towards the local rehabilitative services (when the family has not yet been in touch with it and baby needs motor rehabilitation),
- providing an abilitative and supporting team within our Foundation (when the development of the child is undermined by difficulties related specifically to the sensory disability).

The common goal of these different services is to monitor the development of these children and their relationship with parents, trying to promote mental life, intersubjectivity, a strong attachment system and a better reciprocal understanding. Such a service has clinical and research aims. We collect data to measure important indicators (well-being and developmental level of the child, parents’ mental representations, their level of distress and anxiety and changes within parent-child relationship). Questionnaire, interviews and video recording of interactions are also used.

W9

Rehabilitation of persons with deafblindness with the help of technical aids

O. Smirnova

Rehabilitation Center OTOFON for the Deaf, Moscow, Russian Federation

The sense of hearing is of great importance for human practice in general. And it is easy to imagine even the greater importance of this sense for persons with total or partial vision deficit, who can not see environment at all or can do it only partially. Even insignificant sound signals ignored by ordinary people may be of importance for the blind.

In general the sense of hearing provides blind persons with the possibility of normal communication, which is the basic condition for compensation of their impairment with its consequences. Of course blind persons have to use their hearing in the course of their activities more often than ordinary persons. This is why deafblind persons have to use their hearing aids for their both ears and have also to use some other technical aids (like the FM systems) which are very useful in combination with ordinary hearing aids.

Using hearing aids, FM systems and other communication systems, persons with deafblindness can communicate with other people knowing no special ways of communication (the signs, the Braille system, manual alphabet etc.). These technical aids make it unnecessary for medical and social staff (as well as for other people whom persons with deafblindness may address) to be trained in those special communication methods (or minimize such a necessity).

About a half of all the deafblind population consists of the people having some residual hearing and they can (due to the compensation possibility) perceive oral speech of other persons (either loud speech or speech amplified with hearing aids). But they need prolonged medical, educational and special technical aid to be trained to use their residual hearing efficiently.

The main problem in the field of personal hearing aids is to make sure that the hearing aid would help to organize natural life of a deafblind person in the way of oral speech development; the hearing aid must be not simply an artificial aid but a basic system of vital importance for any deafblind person.

W10

Tell me the words!

C. Blouin, C.-M. Pylouster

CESSA Larnay - Biard, France

We are EJE (Educator for young children) and psychologist, at the CESSA. The CESSA is a center for deaf blind children in Poitiers (France). The children, in the center, have the double sensory impairments, at different degree, often with the presence of associated disorders or handicaps. With their sensory impairments, children have a difficult access at the world, and at the relation and the communication.

So, different problems emerge, like the relationship, the communication, the comprehension and the referential process. The children don't have a coded language or they have a poor language with a few words, only. The non verbal communication is not always efficient. So, we decided to use the "counting rhyme" (les "comptines", in french), during an activity "put in play stories with object" and during less formal times.

After uses, we establish that the uses of counting rhyme help and facilitate the relation between the adult and the deaf blind children.

But what is a counting rhyme? Singing a counting rhyme for the child without handicap is, often, a natural and spontaneous act. This is a time where the different sensory afferences are unify. All the senses are awoken and unify in the counting rhyme's space.

The counting rhyme, beyond the playing aspect and pleasure for the two partners, participate to accompanying the child towards essential discoveries (like the discovery of the other(s), of the child himself, of the exchange, of the emotions, the body, the language and the culture).

The counting rhyme give a structure at the relation, help to the co-construction of a story and help the child to become a subject in this space and time.

The activity "put in play stories with object" give an answer at the child's project: the development of the exchange, the relationship and the communication.

The counting rhyme have helped the play, the elaboration of a relation between the child, the other and the object.

W11

Creating Teachers' Training Guide on Orientation and Mobility for Educating Specialists in the Field of Deafblindness . Russian Experience

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¹Federal State Institution Children's House for Deafblind, Sergiev Posad, Russian Federation; ²Perkins School for the Blind, Watertown, MA, USA

The Children's House for Deafblind in Russia is presenting the educational program on Orientation and Mobility aimed at training and re-training specialists working with deafblind in this region .

It took a few stages to work it out .

- Conducting theoretical and practical workshops on Orientation and Mobility by Mr.Dennis Lolli , Regional Coordinator , Perkins School for the Blind .
- Defining the plan of developing Teachers' Training Guide .
- Introducing modern techniques in teaching Orientation and Mobility into practical activity .
- Resuming results of scientific research .
- Designing photo and video materials of practical approach .
- Conducting training workshops for the staff of the Children's House for Deafblind , Russia .

Teachers' Training Guide includes :

- Training Manual for Educators on Practical Teaching Orientation and Mobility Skills of Deafblind and Blind Children with Additional Disabilities .
- CD –Rom , containing photo and video materials , illustrating practical orientation skills .

Goals: Introducing Teachers' Training Program , developed in cooperation by specialists of Children's House for Deafblind in Russia and Perkins School for the Blind , for effective education and re-training of the staff in the questions of teaching skills of Orientation and Mobility to children with multiple developmental disabilities .

Questions :

- Do you have your experience in creating similar materials ?
- What kind of practical materials do you consider optimum to illustrate theory ?

W12

How children with CHARGE-Syndrome make us reassess our educational principles: observations and experiences of two teachers of the Taubblindenzentrum Hannover (Education Center for Deafblind Children)

T. Geck, S. Runge

Deutsches Taubblindenwerk gGmbH – Hannover, Germany

Content. Our presentation describes the behaviour of two pupils with CHARGE-Syndrome and shows some ways how to react in an appreciate and empathic way.

Description. After a short introduction of the Taubblindenzentrum Hannover and a description of some special aspects of the CHARGE-Syndrome we will introduce the CHARGE -caused behaviour of two pupils and possible ways to face their behaviour (partly by video).

Purpose. A well known educational rule says that children do always follow an inner reason for their behaviour. With children with CHARGE-Syndrome this sense is often well hidden for us. Only a true knowledge of these children, their behaviour and the special problems of the CHARGE-Syndrome will enable us both to value their actions and to react properly. Often enough we have to change our familiar focus in order to match their action with their inner motives. This will help to de-escalate stress situations; at least it might help to make unavoidable tensions more bearable.

Questions

Do you share our experiences?

Do you think that our approach can be put into action in a general way?

If so, what general set-up would it take?

W13

Drama in everyday life

J. Mölgård, V. Eriksson

Resurscenter Mo Gård AB - Finspång, Sweden

It has during a lot of years been known that the interaction partner is of major importance for people who are congenital deafblind when it comes to the development of communication. To create communication demands a present condition, that the interaction partner is qualified and has an emotional involvement with variation and that this creates quality in the interaction which leads to further development.

Sense impressions fill an important function through giving support to experiences. It can be about using the secure and common as a base and to dare to use your own role as an interaction partner as an instrument and offer physical and sometimes more incisive experiences in everyday life. With drama in focus we get the opportunity to involve the whole person, both body (tactility) and mind (interaction) and find a possible way to mutual experience between the involved persons.

In our presentation we want to show the interaction partner's role through drama in everyday life. We want to show the importance of an interaction partner who dares to offer her/himself, to be observant and to take advantage of what happens and to use her/his fantasy. By using these skills we can attract to common experiences which we later can take advantage of for further development of communication.

The presentation proceeds from a short theoretical introduction and then passes on to film sequences on a video. These sequences will help us to describe the interaction partner's dramatically importance for sense experience in different situations and activities. Drama is shown in everyday life with help of playing and also by getting daily routines full of impressions by help of the interaction partner's big, clear, rhythmical movements and exciting style.

Issues:

- How do we make daily life exciting and dramatic?
- How do we create understanding about the importance of the interaction partner's contribution in the development of the communication process?

W14

The meaning of communication in relation to challenging behavior in a young man with deafblindness

J. Wiese, A. Schlagmüller, R. Oerlein

Blindeninstitut Würzburg – Würzburg, Germany

Michael is a 20 year old young man with congenital deafblindness and intellectual disabilities. Since two years he is a student in our institution, where he lives together with 4 other young people with deafblindness in a residential group. In the years before he was taught in a school for students with blindness. During this time he learned a few signs of daily life like EATING, SLEEPING, TOILETTE. Because of increasing massive self-aggressive and aggressive behavior his parents and caregivers decided to send him into our institution with the assumption that Michael needs to learn more signs to communicate.

With this presentation we show the development of Michael during the last two years. In short video sequences we can see his change from an unhappy person into a more satisfied, happy young man although he does not use more conventional signs until now. The following questions will be addressed:

- What kind of intervention is important for people with challenging behavior by considering that this behavior has a function for the individual?
- Which role has the quality of social interaction?
- How can we consider the importance of communication and improve it in our practice?

The purpose is to share experiences and to discuss ways of maximizing the quality of social interaction and communication with children and adults who are deafblind.

W15

The challenge of eating and drinking in CHARGE Syndrome

S. Rose

Sense, Family Education & Advisory Service - Barnet, UK

It is well documented that individuals with CHARGE syndrome may face difficulties with eating and drinking. There is emerging literature that documents the prevalence of these issues and support intervention for such difficulties.

This presentation will provide a review of current literature on the prevalence and nature and range of difficulties and subsequent challenges presented. An overview of the features of CHARGE that relate to difficulties when eating and drinking will also be provided. It will outline some observations on the nature of the challenges facing children with CHARGE seen at our centre in North London. These challenges will be discussed in the context of case studies to illustrate individual challenges and possible management strategies.

It is recognised that the early oral experiences of children who experience challenges eating and drinking have an impact on later development and prognosis. The involvement of cranial nerve dysfunction in CHARGE leads to a high percentage of children having eating, drinking and swallowing disorders – up to an estimate of 80% of all cases (Sanlaville and Verloes 2007). In addition there are numerous other factors and co-occurring features that impact on these difficulties, combined these present significant challenges for the child that are often seen as 'behavioural feeding issues'.

Case studies will identify some of the 'mealtime behaviour' of children seen at our centre and begin to develop some understanding of the challenges facing this group of children and the sort of support that could help to overcome them. This is an area where there is less literature and it is hoped that this paper will begin to contribute to a greater understanding of these issues for this group of children.

W16

Assessment of Cognition in Relation to Congenital deafblindness – from sensation to dialogue

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It is a challenge to assess cognitive abilities in persons with congenital pre- linguistic deafblindness. The cognitive function is literally embodied and expressions due to communicative hindrance difficult to interpret. Psychometric instruments, analytical models and norms are mostly missing and for that reason a Nordic network has been established. As the subtitle "from sensation to dialogue" suggests it is a multidisciplinary project. Increased knowledge about tactile cognition is a prerequisite and methods applicable in optimal settings must be developed to secure validity. An inquiry study indicates that professionals are deeply affected by the complexity of assessments. There are differences depending on profession and place of work, concerning chosen methods and conduction of assessments and analyses, but Transdisciplinary mappings in which different professionals as well as relatives and staff take part are preferred in general. Research- findings highlight methodological issues and contribute to an understanding. But cognitive expressions might look very different from norm – based expectations and observation cues are indispensable. Assessment – tools must be developed from clinical experiences. By analysing video- sequences on interplay and by conducting narrative mappings in which relatives and staff are describing the individual in focus related to her social- and physical- environment, a relational and functional narrative is created. When connected to physiological and neurological data and given a developmental frame a structural and functional evaluation of the tactile working – memory in vivo during situations of shared attention can be done. But how to make observation – cues clear, operational and even standardized without losing validity? How to best integrate information from different levels, let's say neuropsychological findings and observations of interplay; communication and problem - solving?

W17

A dialogical approach of staff development

A. Nafstad, J. Souriau, F. Bertheau

CRESAM - Migné-Auxances, France

As a student in the Master on Communication and Congenital deafblindness (Groningen University) and a consultant for the French National Resource Center for Deafblind Persons (CRESAM), I have the project to address the question of staff development from a dialogical perspective. This approach uses the concepts of dialogicality and dialogism as they are defined and developed in the Master and proposed by scientists like BAKTHIN, MARKOVA, LINNÉL and KOSHMAN.

I used my thesis to explore the potentials of this approach through identifying the theoretical correlations and practical connections existing - or potentially existing- between:

- a Dialogical approach of the Communication with the CDb Subjects - based on the contents of the Master.

- a Dialogical approach of Professional training based on the theories of Dialogical learning.

Starting from the relevance of using video as a tool for observation and analysis of social interaction and communication, the method consists in

1- Filming professional-CDb dyads during an "activity" which does not belong to daily life routines and which is designed to trigger expressions about family life (3 sessions).

2- Filming the meetings where these professionals take part in the video analysis sessions of the dyads conversations (3 sessions, one after each dyad conversation).

These video clips will be described using as units the communicative projects (as defined by LINNEL i.e. a sequence of utterances where conversationalists collaborate towards a same aim). The analysis of these data will use quantitative and qualitative parameters:

- The quantity of expressions from the CDb persons.
- The balance between imperative and declarative utterances.
- Indicators of reciprocation of perspective.
- Analysing the trajectory of the concepts (during the six situations) and describing how they are co-constructed and co-implemented.

W18

Ready to face the world

H. Brink

FSDB - Enskede, Sweden

Young people with deafblindness face a very tough challenge when it comes to find work in Sweden. Many of them are left outside the work line which increases mental and physical illness as part of isolation. I am running a project, studying the way that should lead to work, to find out what the young people are receiving from school and others around them in order to be equipped to meet the world and get a job. Who is there to help when needed? How is the cooperation between professionals? How do these young people see themselves? What do they need in order to find work? What kind of services are there to provide service for young people who need a job? How do professionals around these young people encourage self-determination in order for them to increase their empowerment? The project covers quite a lot but mainly focuses on the goal: employment for young people with deafblindness.

W19

Supporting the Sexuality and Relationship Needs of People who are Congenitally Deafblind within a Strong Current of Safeguarding

M. Foster

Sense - Birmingham, UK

Content. Case studies and a project report will illustrate how one Sense region supports vulnerable young people and adults with congenital deafblindness to make progress, within a strong current of safeguarding that aims to reduce isolation and empower individuals.

Description. A Power Point presentation, supported by DVD footage.

Purpose. To share how a Sense regional consultant on deafblindness/sexuality and relationships and care staff design support plans for young people and adults who are congenitally deafblind. Through assessment of individual needs, we aim to be pro-active in identifying ways to enable young people and adults to learn how to manage their sexual needs appropriately within a strong current of safeguarding.

Many people with congenitally deafblindness still lead isolated lives, devoid of any experience of real friendship, closeness, love. Their carers may be overprotective and often see themselves as 'friends' too, because the idea of enabling such vulnerable people to get to know other people better is seen as too risky.

This paper documents how it is possible to extend the personal and social networks of young people and adults with congenital deafblindness, enabling them to know what might be possible in terms of developing friendships and relationships with people other than their carers and families.

The author will describe how a project 'PRISM' (Promoting Relationships in Sense Midlands) set out to explore innovative ways of bringing people together, with an emphasis on making real and meaningful contact with their peers through paired and group experiences. One strong aim of this project is that the people we support will no longer be stranded on a Desert Island, but rather, be carried along on an exciting wave of discovery!

Questions.

1. How can we ensure vulnerable people are protected but enabled to experience the joy and pleasure of close friendships and relationships?
2. How can people who are congenitally deafblind get to know about another person safely, through touch?

W20

To be a mother of the child with CHARGE

A. Dunikowska

Association for the Welfare of the Deafblind - Warsaw, Poland

Content. Brightness and shadows of being parent of the child with CHARGE

Description. My child with CHARGE : the beginning and the present – her situation at the primary school for non handicapped children, her strong and weak sides, her problems and various ways of trying to help her. The engagement of parents and the school - cooperation with supported teacher. Situation at home – relation with the sibling and within the whole family. Possibilities of meeting another parents of children with CHARGE in the Parents Section existing within the Association for the Welfare of the Deafblind. Participation in the courses for parents and deafblind children and their role.

Purpose. -To show the role of the parents in educational work with the child with special needs.

-To analyse specific characteristic of the child with CHARGE and the consequences of that.

-To exchange the experiences of being a mother of the child with CHARGE.

-To exchange the experiences of being a mother of two children – where one of them has a CHARGE and another is hearing and sighted child.

Questions.

1. Do other parents observe similar problems at school and may it be connected with specific characteristic of the db children with CHARGE ?
2. How to solve specific educational problems of that child?
3. Are the supported teachers well prepared to help db child in the regular school?

W21

Tactile orientation boards

M. van Welbergen

Bartiméus - XM Doorn, The Netherlands

Orientation and mobility is one of the functional areas that is influenced by congenital deaf blindness. It requires a great amount of effort to make a mental picture of the environment based on tactile clues. Even in familiar surroundings it can be difficult for persons with congenital deaf blindness to get a clear overview and they can easily lose this overview, for example when furniture is moved and changed or renovation takes place. The consequences of a lack of overview are disorientation, frustration or dependency and passivity. Persons who cannot orientate themselves in their environment rely on others to help them move around, even though they have good mobility. Supporting these people involves more than helping them moving around. It means supporting them to learn sufficient ways to orientate. Tactile clues can help them in this orientation.

In a facility for adults with congenital deaf blindness in the Netherlands, tactile orientation boards were developed with the purpose to support orientation. The boards are placed next to the entrance of rooms. The material on the boards is specifically chosen to show the function of the room: for example the same leather of the couch of the living room or bathroom tiles. The introduction of the boards is accompanied with instructions for the caregivers how to encourage their clients to explore the boards.

We present the experiences of one group home by use of video-fragments that were taken before and after the introduction of the tactile orientation boards.

Questions:

1. Does the tactile orientation board help the deaf blind with their orientation?
2. Is it possible to use the tactile orientation board in training mobility ?

W22

Being a balancing artist. A new way of looking at life with deafblindness

F. Krijger

DoofBlinden Netwerk - Leiden, The Netherlands

This workshop will (re)define life with deafblindness as balancing act and a person with deafblindness as a balancing artist. This metaphor opens new perspectives on life with deafblindness by emphasizing the capacities deafblind people develop by force.

A deafblind person, congenital or acquired, is a balancing artist by definition. Living life with deafblindness asks for a constant awareness of one's capabilities and incapacities of one's energy and physical limitations. It asks for focussing and letting go. The life of a deafblind person, therefore, takes place at the tightwire that is stretched all over everyday life.

A deafblind person needs to balance his strength, speed and weight. And it takes courage, flexibility and endurance. Training these skills is important for a deafblind person in order to maximize the use of his capacities. In this workshop I will detail these skills.

The use of balancing act as a metaphor for life with deafblindness has two important advantages. Firstly, the metaphor strengthens one's self-esteem. Presenting yourself as a fabulous balancing artist feels very different from presenting yourself as severely handicapped. It may support deafblind people to find their own strength and use it. Secondly, it brings together the reality of deafblind and well-sighted/hearing people. The metaphor of the balancing artist magnifies the reality of all and may therefore clarify the essence of deafblindness to both realities. This opens the way to estimate deafblind people at their value, because what they have to achieve is admirable.

The concept of balancing act may thus provide a valuable guideline for further development (of rehabilitation programs) for deafblind people.

An element of this workshop is a visualization of walking on the tight wire as a balancing artist in order to make the metaphor more tangible.

Questions

- How do you basically approach deafblindness? / What is the focus of deafblindness within your organization?
- If you look at yourself/ the rehabilitation program you offer/ the research you do from the image of the balancing artist, what can this image offer you?
- Do you miss elements in the balancing artist-framework as it is presented to you in this workshop?

W23

“Responsible Inclusion”: Considerations in Providing Access to Quality Education for Children with Deafblindness

S. Perreault, D. Gleason, D. Lolli

Perkins School for the Blind - Watertown, MA, USA

As the philosophy of “inclusion” into local schools of all children with disabilities expands, we have identified both common policy and regulatory barriers towards expanded educational services and issues to consider in providing accessibility for children who are deafblind.

We will discuss policy and regulatory barriers towards expanded education services for children who are deafblind, including:

- o Lack of a functional definition and system for identification
- o Lack of training for special and regular education teachers
- o Funding structures based on needs of children with a single disability, including high teacher: student ratios
- o Limited knowledge of curriculum accessibility
- o Inadequate systems for student assessment and evaluation
- o Minimal support and training for families to be included in education planning
- o Missing linkages to other government agencies

A current concern is the promulgation of the philosophy of “Inclusion” into local schools of all children with disabilities. While laudable in intent, often the models developed and implemented at national levels have not worked well for children with deafblindness. Some policies and practices provide non-existent or inadequate supports, rendering education inaccessible.

We recommend the following issues be considered in the development of comprehensive programs addressing “education for all” in order to provide accessibility for children who are deafblind:

- o Systems of evaluation and identification
- o Continuum of services
- o Range of placement options
- o Individualized education
- o Systems of personnel development and training
- o Parent training
- o Expanded time for education

The main purpose of this presentation is to stimulate discussion on responsible inclusion policies and practices that promote quality education for all children with deafblindness.

Discussion questions include:

- o What factors contribute to the successful inclusion of children with deafblindness?
- o What factors limit the success of inclusion of children with deafblindness?
- o What policy and regulatory recommendations would you make?

W24

Experience and expectations of parents of congenital Deafblind children with cochlear implant - case study

B. Rönnåsen, A. Boström

National resource Center for Deafblind - Gnesta, Sweden

The material for this workshop is retrieved from a study (2008) performed by the National Agency for Special Needs Education and School Resource Center for Deaf Blind in Sweden.

The study includes six children with congenital deaf blindness and Cochlear implant (CI) and is based on interviews and video analyses. The interviews were made with the aid of a schedule of questions for screening of congenital deaf blind children with CI composed by psychologist Jesper Dammeyer.

The six children included in the study are between five and seventeen years old. They are all deaf and two of them are entirely blind. Three of the children are visual impaired and one child is "socially blind" with the diagnosis Cortical visual impairment (CVI). Two of the children have the diagnosis CHARGE. In common for all six of them are multi-disabilities, poor balance and suspicion of mental retardation. The children have between one to eight years experience of having CI. Two of them have bilateral CI.

Through case studies we will try to show how these children have adapted to their CI. The presentation will also treat how the parents experience the children's interaction and communication skills before and after receiving CI. We will point out the resemblances and differences of special interest. We will also describe the parents view on CI, both how the interaction with their child works and how the technology works.

We will show video recordings of the children to illustrate the results of the study.

W25

Meaning construction in communication between congenital deafblind children and their communication partners: an intervention study

S. Damen, M.J. Janssen, A.J.J.M. Ruijssenaars

University of Groningen - Groningen, The Netherlands

An intervention model of meaning construction is applied in a pilot study involving two congenital deafblind children and six communication partners.

In the workshop an intervention model is presented and the first results of it's application. The intervention aims to foster the development of mutual understanding between congenital deafblind persons and their seeing and hearing partners. The model is based on both general principles of diagnostic intervention in special education and on theories about the importance of meaning construction in communication. An overview of the research literature regarding approaches in deafblind education shows that most interventions only address single elements of the dynamic dialogical interaction process between two communication partners and forget important characteristics of the process, such as the principle of joint construction of meaning and the influence of the communication context.

The intervention model is applied in two single case studies of deafblind children and their communication partners. Six communication partners received an evidence based training to improve their interaction skills (CONTACT) and complementary training and support to become sensitive and skilled with regard to aspects of meaning construction, for example taking the perspective of the deafblind child and tactile meaning negotiation. Changes in the communication context where also applied.

Questions

- Several approaches in deafblind education focus on single elements of the dynamic communication process. What is needed to make professionals aware of the importance to look at it differently and treat communication as a dynamic process in which communication partners are co-actors?
- Are there professionals who have experience using persons with acquired deafblindness to teach parents and teachers how to negotiate about meaning in a tactile way and what are the results?

W26

A Man becomes an 'I' in relation to a 'You'.

M. Estenberger¹, K. Bruder²

¹National Resource Centre for Matters Regarding Deafblindness - Finspong, Sweden

²Resurscenter Mo Gard - Finspong, Sweden

The National Resource Centre for Matters Regarding Deafblindness has, in cooperation with the Mo Gård Habilitation, been involved with a developing project focusing on a person with congenital deafblindness over the past two years.

We would like to describe both the project and the strategies we have applied in the development of social interaction and communications.

Our work focused on an adult man with congenital deafblindness, who had neither previously been identified as deafblind nor had previously been given the opportunity to take part of the specific knowledge and habilitation/care within the field. The man was severely self-destructive and acting out when he came to Mo Gård.

In the workshop, we intend to describe and illustrate with videos those strategies with which we have worked. Two processes of development were identified, one being "You and I" (the dyad) and where the focus is primarily on the relation; the other developing process was "You, I and it" (the triad), with the focus here primarily on the third element. While these two processes subsume each other and occur in parallel, during the development of the project we chose to attempt to distinguish them individually.

The different strategies were tried out through observation and videos.

In the first developing process "You and me" the following strategies were used:

- To create confidence and security through closeness
- Shared experiences
- Do the same
- Do together

In the process "You, I and it" we worked with the following strategies:

- To observe existing expressions
- To create new expressions
- To make conscious these expressions.

Questions:

1. How can we secure the continuation of the work after the termination of the project?
2. Provide suggestions of other relevant theories and strategies that could have been successful/appropriate?

W27

The role of rehabilitation for dysphagia at an early age

C.M. Vigo, R. Belardinelli

Lega del Filo d'Oro ONLUS - Osimo (AN) - Italy

Dysphagia is difficulty in swallowing which may have many different neurological, structural or cognitive deficit causes. In recent years, swallowing problems have increased noticeably in the children who have come to our Centre for early intervention. In order to obtain results and improve the quality of life for these children, it is very important to take action on chewing/swallowing from the earliest possible age.

The rehabilitation process used involves the development of a programme based on the patient first being observed by the speech therapist during meals, followed by a medical diagnosis and where necessary, instrumental examinations (FEES-VFS).

Information obtained from the evaluation is used by the interdisciplinary team to make recommendations about correct posture, the type of nourishment and food to be taken and the setting up of an individual therapeutic programme with passive and active stomatological physiotherapy. Particular care and attention is paid when treating children with a naso-gastric tube, a PEG and/or tracheostomy tube.

Stomatologic physiotherapy becomes an important preliminary part of any speech therapy which requires acting on breathing, in the sense of starting or augmenting nasal respiration, learning to blow the nose, attention to noise-sound-word etc., and on verbal communication, increasing it or finding alternatives, in agreement with the psycho-educational team.

All data for verifying the results will be presented.

The technical and scientific aspects will be presented using case studies.

W28

The Swedish National Experts' Team for the diagnosis of persons with Deafblindness – a multi-disciplinary team in Sweden

C. Möller, L. Falkensson

The Swedish Institute for Disability Research, Örebro University Hospital – Örebro, Sweden

Sweden is a small country with approximately 9 million inhabitants and around 2000 persons with deafblindness. The Swedish National Experts' Team for the diagnosis of deafblindness is composed of experts with long experience of deafblindness who are working together on a national level to improve the possibilities for persons with deafblindness to get a correct medical and functional diagnose. The experts cover different fields such as ophthalmiatrics, audiology, psychology, genetics, psychiatry, pediatrics, social and pedagogic sciences. It has been operational for 13 years, and have diagnosed more than 90 families with different complicated etiology of deafblindness. Persons with deafblindness, their families and relatives, hospitals and institutions can refer to the team. Reasons are manifold and in many cases the lack of correct diagnose hampers correct rehabilitation. The goal is to give a correct clinical and genetical diagnose but also to evaluate strengths and weaknesses in communication. When the evaluation is completed, the results and recommendations will be presented to the person with deafblindness, the family and all local caregivers in the community. Examples of different medical and functional diagnosis will be given.

W29

Tools for Change: Developing Educational Service Guidelines for Students who are Deafblind

M. Riggio, B. McLetchie

Perkins School for the Blind - Watertown, MA, USA

In all of our countries, as we seek to develop a strong system of services for students who are deafblind and their families, it is critical that general educators, special educators, program administrators and policy makers have a clear understanding of their very unique and complex needs. It is therefore our responsibility to convey this information in a cohesive and well planned manner both as text and through training.

This will be an interactive session where presenters will use the development of Deafblindness: Educational Service Guidelines (Riggio, M. & McLetchie B.) and other related publications as guides for participants to develop their own way of clearly articulating the rationale for and scope of services needed by students who are deafblind. In addition a strategic plan for companion countrywide trainings of administrators at multiple levels will be described.

Some of the key themes that will be addressed are that:

- Students and educational teams require the guidance of a deafblind specialist who is someone with the knowledge and skills necessary to guide planning and to provide technical assistance and direct services.
- Communication, which is the foundation for all learning and the building of social relationships, is a primary need that must be addressed in a thoughtful and comprehensive way when developing and implementing the Individualized educational program for students who are deafblind. Most students require one-on-one communication support in order to access the learning and social environments. This may be in the person of an intervener, who is a paraprofessional with specific training to meet the needs of students who are deafblind.
- It is important that administrators at multiple levels work collaboratively and creatively with existing resources, and develop new resources when necessary to expand state capacity and to assure that students who are deafblind receive the specialized services necessary to have equal access to education as their sighted - hearing peers.

W30

Support of the Deafblind Persons on the Work Market

M. Książek, G. Kozłowski

Special Educational Center for the Blind - Warszawa, Poland

Content. Realisation of the project "Support of the Deafblind Persons on the Work Market"

Description. Project will last or 11 months. It assumes identification of at least 480 deafblind persons in the age from 16 up to 50 years old. Participants of the project may be provided with the necessary rehabilitation equipment. It will be carrying 8 workshops (each of them including rehabilitation training and vocational support) and other forms of support. At the end of the project we would like to find a job for at least 5 deafblind project participants.

Purpose. To show interesting example of the national proposition of the support handicapped people on the work market.

Questions.

1. Are there any similar project running on the national level running in the other countries?
2. What is the best practice of helping deafblind people to find a proper job?

W31

Tactile – bodily elements within togetherness in the communication with a woman who is deafblind

M. Martens

Viataal - St. Michielsgestel, The Netherlands

Content. Case study on tactile communication.

Description. In a case study is in search for evidence based practice observed how tactile communication is related to togetherness. A literature review learns that regarding tactile communication it is of importance to focus at three topics, such as 'touching', 'embodiment' and 'communication'. Tactile-bodily elements are thereupon formulated for social interaction with people who are deafblind. From a psychological point of view it becomes clear what people drives to togetherness. Togetherness can be seen as 'two people existing as available to each other in each others minds'. Dialogism appears to be an indispensable mechanism in the togetherness, in which the negotiation process is the essence of it as shown by the results of the case study. This will be illustrated in two video sequences in the communication between a woman who is deafblind and her mother.

Purpose. It is the main purpose of this workshop is to reflect on tactile communication regarding social interaction with a woman who is congenitally deafblind and her communications partner. Therefore, an explorative case study is presented illustrated with two video fragments.

Questions.

What makes a human being interesting for people who are congenitally deafblind?

How can tactile communication be improved?

Which prerequisites for tactile communication can be formulated?

W32

Challenges in family life

B. Enggrav

Eikholt National Resource Centre for the Deafblind - Drammen, Norway

When the adults have acquired deafblindness : A model for working with families and couples.

Families

Main question/for discussion:

How can we help the parents to explain their difficulties with the deafblindness, and help families to communicate?

How can we help the children when their mother or father has acquired deafblindness?

If the parent's vision or hearing impairs, it influences on the family members. Misunderstandings in communication can increase and the impairment can lead to shift in role identities for both adults and children. I want to present a model for creating courses for families, using a case. I will show the process that takes place within the course. The planning involves the family member who has acquired deafblindness. I will also tell how we organize and implement the course.

Couples- "listen with your heart"

Main question/for discussion:

How can partners be a good support for each other? When one of the spouses has acquired deafblindness, it can be a challenge to communicate with their partner. Living together can be difficult. And even harder when vision or hearing impairs.

Together with experienced pedagogues, Eikholt organizes/offers a course that we call "to listen with your heart". The course is built on PREP. (Prevention and Relationship Enhancement Program). PREP is one of the most comprehensive and well respected divorce prevention/marriage enhancing programs in the world. PREP is a skills and principles building curriculum designed to help partners say what they need to say, get to the heart of problems, and increase their connection with each other.

Together with users/participants we have adjusted this program to couples where one of the partners has acquired deafblindness. I will also present how we can use tactile forms to ease emotional communication between the spouses throughout the course.

W33

“Sliding doors”. Ideas, issues and best practice for developing ways of communication using technological devices with deafblind children at an early stage of development

M.M. Coppa, M.L. Orlandoni, E. Orena, M. Spilotri, F. Accorroni

Lega del Filo d’Oro ONLUS, Osimo (AN) - Italy

Children with serious sensory deficits and profound mental retardation need the commitment of multidisciplinary support to see them through their growth and evolution in different areas of development.

Observation of relationships using setting, the collection of structured data (Impact system) and videoanalysis of patterns of adult/child learning interaction, allow us to identify non-verbal and prelinguistic co-regulation processes which are very important indicators for the creation of a range of communications .

The use of technological aids in the rehabilitation protocols of children with very serious neuro-motor and sensory conditions does not substitute for, but integrates the possibilities of active interaction and communication by the children. Programmes centred on C.A.A. Involve the use of switches , microswitches and Vocas, which support the children in their primary need requirements and in the possibility of initiating games and pleasant sensory stimulation. Technological aids stimulate self-determination and encourage the growth in children of awareness of the processes of interaction and co-regulation with the environment.

W34

The use of digitalized short story with closed caption and video description in the teaching of reading to a third grade student with deaf-blindness

J. Rodríguez, C. Iris Soto, M.V. Diaz, M. Sanabria

University of Puerto Rico - Aguirre, Puerto Rico, USA

A single subject research was conducted using digitalized short stories (DS) with closed caption (cc) and video description (vd) to teach reading to a student who is deaf-blind and is included in the third grade in a regular school. The purpose of this presentation is to share the results of this single subject research and to make recommendations on the use of this multimedia technology to foster the communication-oral and in sign language-in students who are deaf-blind. The subject of this research has been included in a regular school since the kindergarten and is in the third grade (academic year 2008-2009). CC Latina digitalized, closed captioned and described (vd) the stories used in this research based on the recommendations of the principal researcher and the teacher of the student with deaf-blindness. A baseline on the student’s vocabulary was established prior to the intervention. The results tend to support the assumption that the DS with cc and vd, foster rich communication interactions and enhance the student’s vocabulary that is needed for reading comprehension.

Questions

1. What are the criteria to determine which student with deaf-blind could benefit from this multimedia technology?
2. Which short stories would you recommend to be digitalized, captioned and described?
3. Why do you recommend describing the pictures of the short story?
4. Can the parents use digitally stories with cc and descriptions at home?

W35

Communication and Language

N. Golovan

Association of Social Support for Deafblind People in Russia “Elvira”

Moscow, Russian Federation

Review of main factors and problems of communication and language development among deafblind people.

Deafblind people carry out communication with surrounding people and between themselves by diverse ways and with the use of various means of communication and language. It depends on the age when deafblindness came, the type of deafblindness, the quality of special education, activity and abilities of deafblind person.

Congenital deafblind people imagine the world around by tactile way. Adequate perception of the world around and communication for these people are not possible without special education.

Acquired deafblind people significantly differ from congenital ones. They keep ideas about the world around from their previous experience (before deafblindness) and spoken or sign speech.

The urgent need in communication for deafblind people is their reaction for social isolation. Communication with surrounding people positively influence the language development (mainly spoken language) of deafblind people. The development of technical aids and communication technologies is the only possible way to increase communication and access to information.

Interpretation of low quality often leads to inadequate behaviour of deafblind people and to the problems regarding their relations with other people.

It is necessary to improve the quality of guide-interpreters and professionals training as well as speech training and development of deafblind children and adults.

We have to pay an attention to main problems which prevent deafblind people from communication with surrounding people, language and special communication aids development.

We have to discuss the most effective ways of development of mother tongue and foreign spoken language among deafborn signers. Is it expedient (if yes, how) to train acquired deafblind people with verbal speech in sign language? How (by means of which communication aids or conditions) could we increase the speed of communication of deafblind people from various categories with surrounding people and between themselves?

W36

A model for staff development: Using video analysis to develop skilful, competent interaction partners who work with congenitally deafblind adults

A. Snow¹, P. Howell²

¹Sense North - Robin Hood Wakefield, UK; ²Sense North - Leeds, UK

To provide high quality services it is important to empower practitioners with a high level of skills, knowledge and confidence within their roles. How can we achieve this in inconsistent environments such as residential, intervener and day services?

The purpose of this presentation is to share with you our experiences and the work we have done in the last six years, using video analysis in supporting our staff to develop their practical skills and interaction with deafblind people.

This presentation will describe the 7 principles which we have come to believe, form the basis for staff development. The principles have been developed and based on many years experience of supporting staff to work and interact with deafblind people. They give the practitioner the rationale behind the techniques being taught and enable them to adapt their practice to suit individual needs. In the last six years, we have been putting these principles into practice across all services by the use of 'video analysis' as part of the process of what we call, 'practice supervision'.

The principles cover:

- The aims of the activity?
- Anticipation
- Interaction
- Giving time
- The use of HuH/HoH, physical & verbal support
- Objects of Reference natural gestures and signs
- Experiencing things together with the person not for them

We will also present some pieces of video to analyse. This exercise will highlight how this process assists the practitioner to reflect on their own actions and practice leading to them becoming more effective, skilful practitioners.

We are currently writing a booklet as a tool for staff development, accompanied by a DVD.

Further research questions might include:

- Are there other skills required to become a competent practitioner?
- Is there any research into which principles support development of competent partners?

W37

The importance of the tales in the pedagogic situation

C. Landel, C. Blouin

CESSA Larnay - Biard, France

"To be able to stay sitting in the class room and "listening": for that, the child does have before a message of general implications" (that can be represented by the tales).

This sentence: I take it in a professional instruction about the pedagogy in the language acquisition. This sentence help me to take aware of our pedagogy with the deaf blind children and our lacks. The lacks about the imaginary,

the imaginary's language, that all children, without deficiency, can have with the access to stories and tales. This access help children to put a distance with their archaic fears, that have an impact in the pedagogic acquisitions. And for the deaf blind children? How to help them to put this distance? We don't use the tales with them!

After this establishment and reflexion about the importance of the tales in the development of all the children, and with the approbation of the director of the institution and with the help of the psychologist, I use the tales in a therapeutic way, in my pedagogic work with the deaf blind children.

I use a same tale during eight weeks, in different ways of presentation: shadow-theatre, puppets, masks, sign language, diapositive, DVD of the tale, books (...) to help children to appropriate the story.

During all the sessions, the children can actively participate in making a trace of the tale in their own paper books (by drawing...).

They also have the possibility to manipulate the personages of the story, that we do in a plasticized and moving way, that help them to be actor of the tale.

After a year, the children aren't afraid about the wolf (in a tale with a wolf). The representation of their bodily plan was better and more elaborated.

In class, their attention was better, and the enter in the writing was possible for all the children of the class. This enter in the writing wasn't possible before the works on the tales.

W38

Developing communication systems in young children who are deafblind, non verbal, pre-intentional communicators ; A Case Study of Research and Action

A. McWilliams

Kilparrin Teaching and Assessment School and Services - Park Holme, Australia

In 1963, the Gilles Street Deafblind Centre was established to provide an educational placement for children with dual sensory impairment. In 1978 the name was changed to the Kilparrin Teaching and Assessment School and Services (Kilparrin), a name that made explicit both the teaching and the assessment functions provided by the facility.

Children and students attending the Kilparrin school and preschool programs are representative of the 'low incidence disability' group (approximately 3% of the students with disabilities cohort). In addition to their complex sensory impairments the students have either a significant developmental delay or a diagnosed intellectual impairment.

Services include:

- a school (R-10+) for students with complex sensory and additional disabilities
- a specialist preschool program for children (3.5 – 5.0 years) with complex sensory and additional disabilities
- a Statewide Support Service that provides

-statewide peripatetic support services for DECS preschools and schools in the provision of schooling for children and students with complex sensory impairments and additional disabilities

-a statewide early intervention program for babies and young children (birth – 3.5 years) who are deafblind

-specialist educational resources and equipment for loan through the Kilparrin Resource Centre

Children who have both distance senses compromised require specific intervention to develop communication. At Kilparrin teachers have undertaken an intensive investigation of communication and appropriate interventions.

This presentation will outline this research, findings and interventions put into practice.

Children's participation and involvement is observed.

Scales of assessment have been used which allow teachers to collect evidence of development which can be measured and lead to further research.

Questions:

How do we develop communication strategies which support concept development and learning in young children who are deafblind?

What are the current technological developments in supporting communication for children who are deafblind?

Do we need to develop a course for teachers of the deafblind?

W39

Assessing the Risks of Choking

Kate Lockett, Christopher Fuggle

Sense East - Peterborough, UK

Content. Workshop Presentation – Presentation of Ideas

Description. Everyone is potentially at risk of choking but individuals who have particular medical conditions, underlying syndromes or particular behaviours at mealtimes could potentially be at a heightened level of risk. Within residential and educational services for individuals who have difficulty communicating, we all have a clear duty of care to do everything that we reasonably can to minimise the risk of any person choking.

The level of risk will clearly be different for each person. Some individuals are at no more risk than you or I, but others could be at extreme risk and need the comprehensive input of a qualified medical/health professional who can

- assess in detail
- recommend appropriate support strategies and give appropriate guidance

Sense UK's Healthcare Strategy Group has considered the idea of how to recognise whether an individual may be at heightened risk and has created a Choking Risk Assessment Screening Tool which we would like to share with participants.

Purpose. Everyone is at risk of choking. How can we ensure that people who are at heightened risk are clearly identified and receive the appropriate level of expert support? The Sense Choking Risk Assessment Screening Tool may be a helpful first step.

Questions.

- 1) Is this document a Risk Assessment?
- 2) What about other conditions?
- 3) Where do we go from here?

W40

Dimensions of Communication: A contextual approach to the assessment of communication behaviors and social interaction

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¹ New Alternatives for Children, Inc. - New York, NY, USA; ² Columbia University - New York, NY, USA

This workshop focuses on a contextual approach to assessment of the natural communication skills and social interaction behaviors of children and adolescents who are deafblind. An assessment protocol that incorporates this approach, Dimensions of Communication, will be reviewed.

The contextual framework for evaluation is based on the assumptions of the ecological orientation of human development (Urie Bronfenbrenner): (a) Development and learning result from the interaction of the person and environment over time; (b) It is as important to assess the physical and social environments as it is the individual's communication and social abilities; and (c) We assess not only one's observable behaviors, but the opportunities for learning and interaction, and the styles of teaching.

The presenters have developed and are currently revising the Dimensions of Communication, an assessment-to-intervention protocol. The Dimensions of Communication is an instrument designed to help teachers, educational specialists, speech-language therapists, psychologists, and other service providers evaluate the communication and social skills of children, adolescents, and young adults who have multiple disabilities, including severe or profound intellectual disabilities and deafblindness. It was designed for the assessment of persons whose communication behaviors are primarily nonconventional and/or nonsymbolic (e.g., vocalizations, gestures, body language). This instrument focuses on six specific domains, or dimensions, that can be analyzed to provide a broad picture of a person's communicative competence: Symbol Use, Intent, Complexity, Social Action, Vocabulary Use, and Comprehension. The Dimensions of Communication may be especially useful when standard language tests are not applicable. It offers a qualitative approach to characterize the forms, breadth, and attributes of an individual's communication behaviors when speech may or may not be present. It provides a process that links assessment results to intervention planning.

W41

Improving Participation and Activity for Students with Multiple Disabilities Including Visual Impairments (ImPAct)

I. Amaral¹, B. Elmerskog², J.M. Tellevik², D. Drave^{3,1}, E. Fuchs³, A. Farrelly⁴, I. Prain⁵, E. Storani⁶, P. Ceccarani⁶, M. Skalická⁷ (¹Portugal; ²Norway; ³Blindeninstitut Würzburg - Würzburg, Germany; ⁴Ireland; ⁵Scotland; ⁶Italy; ⁷Czech Republic)

This program offers you tools to find new ways in working with MDVI children. It introduces an approach which enables teachers to move from a developmental, skills base, to an activity based intervention approach. It uses real life activities which are meaningful to the child in the context of his/her life, family and community can then become

the basis for student learning. Moving education beyond training programmes, and expanding the experiences of MDVI children to real life activities gives the child the equal opportunity to participate fully in their community.

The ImPAct MDVI project addressed concerns expressed by teachers of Multi Disabled Visually Impaired (MDVI) children as to how they are expected to integrate the diverse curriculum elements and particular skills they have been taught into a meaningful educational process.

The aim of this project is to develop a holistic teaching approach, based on activities, participation and involvement in real life situations, so that the whole child with MDVI is involved in their complete social and physical context. This is achieved by applying the 5-step working model (Tellevik & Elmerskog 2001), which aims at supporting the development of assessment and planning intervention strategies.

The project ran for 3 years (2003 – 2006) and involved the production of training resources to enable teachers to apply this approach. This booklet presents the results of the project, details the five step model and provides a rationale for using an activity based intervention, as well as guidelines for working with MDVI children based on real life activities.

W42

Identity and disability

B. Latzelsberger

Resource Centre for deafblind people - Wien, Austria

Identity- forming components such as communication and work in the lives of deafblind people – theoretical and philosophical considerations about the huge human topics communication and work. What importance do they have in the lives of deafblind people?

The following points will be pointed out and discussed during the workshop:

Which factors are important in the development of identity for deafblind people?

If ones own identity is the total of the characteristics which differs human beings from others and when this identity is based upon being with other people, what does that mean for the development of identity for deafblind people.

Are the deficits in seeing and hearing and the lack of expression the superficial characteristics of deafblind people?

How do deafblind people develop their identity? Which repressing factors are they confronted with by society and where are the chances and possibilities based? What is our assignment in supporting deafblind people?

A very special meaning for development is the social level, only in this mutual condition from human to human is it possible for the individual to develop. Only in this encounter is the finding and developing of identity possible.

Work plays a central part for the exploitation of the social perspectives and identity. Through what activities, what kind of actions, what kind of work gives a deafblind person the possibility to understand the world? What importance can work have – in the broadest sense – in the lives of deafblind people concerning the development of his subjectivity and identity?

The terms communication and interaction are related to “production” and “work”, as they are determining these processes. From that results that disability is created and exists only in a society created by human beings – and cannot be looked at detached from that.

W43

Participatory research about participation for people with deafblindness

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Persons with deafblindness are often the object of research. Their possibility to participate and influence the research project it self may be restricted. This presentation is focused on participation in research. It is a report of experiences in research with persons with deafblindness involved in the research process like research partner. Issues related to methods and ethics from the perspective of a hearing and sighted researcher and research partner with deafblindness will be explored. Presentation will also explore communication implications due to work with interpreters. Reflections about ethical implications in research with persons with deafblindness will also be explored. Presentation is based on several studies in Sweden during 1997 – 2008 reported inter alia in the Thesis: Impact on participation and service for persons with deafblindness (Möller, 2008 <http://www.diva-portal.org/oru/abstract.xsql?dbid=2027>).

W44

RELATIONSHIPS WITH FAMILIES

Parte one: The emotional aspect, support and training of parents.

Parte two: Is my brother an only child? The experience of siblings.

P.Ceccarani, A. Archibugi, C. Acquaroli, G. Giaccaglia, M. Pallotta
Lega del Filo d'Oro ONLUS, Osimo (AN), Italy

Part one - The emotional aspect, support and training of parents

A deafblindness, because of its severity, leads to emotional upheaval for the parents and the interruption and destruction of their plans for their family.

From our experience of working with parents, accounts of feeling emotional abandonment, loneliness, fragmentation have emerged frequently. When the diagnosis is given there are feelings of confusion, emotional numbness and incompetence.

During the 40 years the Rehabilitation Centre has been operating, we have identified different types of reaction to deafblindness with regard to the ability to face up to the situation and the management of emotions.

The work presents the different reactions, the different adaptive and non-adaptive defenses that the parents adopt in the face of this traumatic event and the route to growth for the parents through group sharing sessions, or Parent-Training and work with their own bodies and movement. The session contents will be presented as well as the learning results and changes made by the parents.

The group work with parents which the Rehabilitation Centre has been carrying out for years, combines verbal, experiential, body and imagination aspects aimed at integrating the different features of the subjective experience.

The model and methods used with parents and the data collected through the years will be presented.

Parte two: Is my brother an only child? The experience of siblings

The siblings of deafblind and multisensory impaired people all too often remain in the background and can have difficulty in expressing their own needs and feelings.

The presentation will investigate this situation and highlight how:

- siblings participate in family life, often playing the part of the "lucky child";
- the responsibilities and expectations, real or imaginary, they have are different from those of the parents;
- they express their emotions and experiences;
- They often receive little attention even from professionals and can be the "most invisible" family members.

Siblings thoughts and wishes can sometimes be most "surprising".

In the workshop the experiences of a self-help group which involved siblings of people, assisted by one of the Lega del Filo d'Oro's services, will be presented. Initiatives undertaken to enlarge the scope of the exercise to other siblings and family members will also be discussed.

The aim of the presentation is to highlight the results and reflections from the experience; to stimulate discussion on the theme with family members and workers involved in similar schemes and also to offer a contribution to the network already operating within the Dbl.

What support is needed to encourage the happy growth of all children and a harmonious family atmosphere?

What could be the strong points of siblings' experience and how could these be transmitted to others?

W45

Congenitally deafblind children and cochlear implant – effect on communication

J. Dammeyer

University of Copenhagen - Brønshøj, Denmark

There has been much research conducted demonstrating the positive benefits of cochlear implantation (CI) in children who are deaf. Research on cochlear implantation in children who are both deaf and blind, however, is lacking. The purpose of this article is to present a study of 5 congenitally deafblind children who received cochlear implants between 2.2 and 4.2 years of age. Ratings of video observations were used to measure the children's early communication development with and without the use of their cochlear implants. In addition, parental interviews were used to assess the benefits parents perceived regarding their children's cochlear implants. Two examples are included in this article to illustrate the parents' perspectives about cochlear implantation in their deafblind children. Benefits of cochlear implantation in this cohort of children included improved attention and emotional response as well as greater use of objects in interaction with adults. The best overall outcome of CI is not spoken language but better communication.

Article published in Journal of Deaf Studies and Deaf Education

<http://jdsde.oxfordjournals.org/cgi/content/abstract/enn042v1>

How to understand development of congenitally deafblind children with CI?

How can habilitation of congenitally deafblind children with CI be done?

W46

Sharing artistic activities and aesthetic experiences with adults with congenital deafblindness – A new perspective on more than 10 years of Scandinavian practice

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During the previous eleven years the Scandinavian associations of parents of children with congenital deafblindness have organised so called “sommerhøjskoler” (summer camps/courses in the folk high school tradition) with aesthetic activities. A group of parents, called “Kulturförbundet”, have invited artists and musicians to conduct courses and workshops for deafblind adults and their partners (parents, teachers, and other staff) from all of Scandinavia. These one-week courses have in recent years taken place on Gotland in Sweden, in Sømådal in Norway, and at Slettestrand in Denmark.

This workshop will present an extract from an ongoing project, that aim at documenting the positive outcome of these summer camps in terms of communication and social interaction between the adults with cdb and their partners.

By way of narration and video examples we will demonstrate how aesthetic activities, if conducted in a specific way, may give support to the partners strive towards a dialogical subject-subject relation with the person with cdb.

This specific way must, among other things, provide:

1. a process oriented and creative frame that helps the partner to let go of the control of the activity.
2. an activity that engages the partner (at least) as much as the person with cdb.
3. a social context in which the expressions of the person with cdb are readily integrated and thereby become easier to acknowledge as valuable for others.

These topics will be discussed in two manners. Firstly, the specific structure of aesthetic activities will be reflected in the theoretic framework of Ellen Dissanayake’s universal aesthetics, in order to establish how these activities of “making special” differ from other activities. Secondly, the potential transfer value of the structure of the aesthetic activities to other more daily life activities will be explained in terms of openness, creativity and “making special”.

W47

Imagination, Intervention and Independence...going beyond boundaries

K. Keyes, K. Patterson

Adult Services – Congenital Deafblind - Newmarket, Ontario, Canada

DeafBlind Ontario Services creates homes where adults with congenital deafblindness can live more independently. Through its supported living arrangements, trained Intervenors, work experience and other specialized support services, DeafBlind Ontario Services gives each resident the ability to enhance their independent living skills.

Currently, DeafBlind Ontario Services supports 44 congenital deafblind adults, each with their own individualized history, abilities and passions. This presentation will illustrate how the current Service Model was developed and implemented to accommodate the needs of ALL the people that are supported by this organization in Ontario, Canada. Based on a “Person - Centered Approach” to goal setting, the Service Model has the flexibility to meet the needs and desired outcomes for the new graduate or the active senior living with congenital deafblindness. By using two case studies, this presentation will outline the differences between two resident’s lives since the Service Model has been implemented.

The presentation will cover how implementing the Service Model impacted DeafBlind Ontario Services’s internal training. To provide quality service delivery through the new model it was imperative to focus on the internal structure and facilitation of training. From this focus came the development of an internal training program called TOUCH™, which stands for Training, Ongoing, Unique, Committed and Holistic. The establishment of a standardized internal training program and unique Service Model also provided the foundation for the Deafblind Ontario Services’ REACH program.

The collaboration of each of these components: supported living, flexible Service Model, and standardized training provides the opportunity and potential to focus on the future on “Imagination, Intervention and Independence...going beyond boundaries” with the adults DeafBlind Ontario Services supports.

Objectives:

- Overview of DeafBlind Ontario Services and why the organization embarked upon updating its Service Model and delivery
- Development and implementation of the Service Model and its tagline “Focusing on the Fundamentals...Imagination, Intervention and Independence.”

- Summary of the three components of the Program Module which outlines the Service Model; Resident Program Portfolio, Service Tracking and Internal Audit
- Overview of Deafblind Ontario Services standardized training - TOUCH™ and Total Communication Curriculum and its impact on consistent service delivery
- Illustrate how this extensive undertaking to the Service Model and Training continues to meet and exceed the expectations of our residents – both in the present and in future
- Share examples of successes of the Service Model and how it has impacted the lives of the Residents supported by DeafBlind Ontario Services
- REACH Program - why and how it was developed and the unique community partnerships it has created

W48

Pedagogical challenges in school related to a child with CHARGE syndrome and congenital deafblindness

W. Andersen, E. Seljestad

Skådalen kompetansesenter, Regionsenter for Døvblinde - Oslo, Norway

Content. Challenges concerning learning and social communication

Description.

- Case study, girl, 9 years
- Lecture, videos, pictures and discussion

Purpose. Our experiences in organizing the classroom for optimal teaching and socialization:

- Dual sensory impairment and learning conditions concerning impressive and expressive language
- Use of interpreter - advantage and disadvantage
- Social and emotional communication strategies are often inadequate

Questions.

- Could it be that myths about CHARGE prevent a realistic look upon the child?
- Could it be that medical descriptions lead us to undermine the child's potentials?
- Spoken language versus sign language versus tactile language?

W49

Unseen and Unheard - A study into the number of people who are deafblind in Western Australia

D. Karasinski

Senses Foundation - Burswood, Australia

Content. Findings of a study in Western Australia into the number of people with deafblindness and the implications for the developed world.

Description. In 2007, Senses Foundation commissioned a study to identify the number, location, age and level of disability of people who are deafblind throughout Western Australia. The findings revealed numbers which place in dispute the estimated incidence of deafblindness in developed countries, such as Australia, which is 20 per 100,000.

The findings are described along with the implications for service delivery and for incidence predictions in the developed world.

Purpose. In developed countries, such as Australia, the estimated incidence of deafblindness is 20 per 100,000. If this estimation is correct, in Western Australia one could expect to identify 386 individuals with deafblindness. However, the study identified 8,800 people living in Western Australia with the dual sensory disability of deafblindness.

This paper looks at the methodology of the study, the findings and the implications for service delivery.

Twelve key findings were determined in the study in relation to demographic variables such as number of people, geographical location, age and gender, level of disability and service usage.

Given the projected increase in the number of older Australians in coming years, and the increased incidence and prevalence of a range of conditions contributing to deafblindness, these numbers can only be expected to increase in the future.

This paper also considers the causes of deafblindness in Western Australia and the implications for service providers in other developed countries.

Questions. Should Western Australia be considering the incidence rates of underdeveloped countries because of the higher rates of deafblindness amongst its indigenous population?

What are the implications for other developed countries from the Western Australian study?

W50

The characteristics of disabilities arising from the birth process: an epidemiological study

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¹Lega del Filo d'Oro - Osimo (AN), Italy; ²Ospedale Pediatrico Bambino Gesù - Roma, Italy

The Rehabilitation Centre of the Lega del Filo d'Oro in Osimo carried out research in collaboration with the Epidemiological Unit of the Bambino Gesù Hospital in Rome to evaluate, using retrospective analysis, the characteristics of relevant cases and the changes to these characteristics through time (since 1968 to 2007). The aims were to investigate the hypothesis that the frequency and gravity of pre-perinatal forms of disability have increased and how the needs of users and the complexity of care provision may have changed.

The Rehabilitation Centre represented a potentially very important focal point for understanding the nature and essence of this problem.

A chart collecting data from 10 sources (perinatal history, diagnostic summary, Ophthalmology, Ear, Nose and Throat, Neurology, Physiatry, Orthopaedics, Dentistry, cognitive evaluation, communication and autonomy) was drawn up. An Access data-base was created.

The study population was made up of 381 patients. The age range was from 3 to 8 years. The statistical analysis presented is of a descriptive, univariate and bivariate type. The data show that in the Lega's 40 years of working, and particularly in the last 10 years, there has been a change.

Premature brain damage cases have almost tripled and those relating to infection during pregnancy have become seven times fewer. In the group of pre-term births, the frequency of those with a degree of severe or very severe dependence has increased more with respect to the rest of the population.

The results indicate that the situation is constantly changing and is becoming ever more complex. This involves educational, methodological, instrumental and environmental choices. The Rehabilitation Centre intends to continue to study the population long term to evaluate how much the degree of disability/severity affects the quantity and quality of life and what new needs have to be met.

W51

Changes Among the Deafblind Population in Russia

T. Basilova, [A. Paykova](#)

Moscow City University of Psychology and Education - Moscow, Russian Federation

Analysis of the data gathered during the last 30 years of observations as well as diagnostic studies of deafblind children and adults (more than 400 cases) in Russia confirms the fact of significant changes in this population which is getting more severely impaired in the recent years. There are less cases of early acquired deafblindness where only periferic impairments of visual and hearing analyser systems take place. We can witness more often the cases of the malformation of brain structure or early impairment of the central nervous system on the cortical level which bring to system disorders impacting the future development not only in the sensory but also in the emotional and intellectual fields of child's development. A special analysis of all developmental case-histories of children having innate and early acquired blindness complicated by additional disorders shows that among this population in different years of observations there is a rather stable number of children who can have a rather good forecast of their psychological development (around 20% of cases). Long-time observations though showed that a part of these children who were seeming to be in a good state from the point of view of their safe abilities got worse while entering into the adolescent and elder age; so at the end they became part of a group of the low functioning blind children with additional disabilities.

As to our presentation there will be precise statistic data on the ethiology and level of sensory impairments in the observed cases of deafblindness, as well as some videos showing different aspects of psychological development in some cases.

At the Conference we would like to discuss the reasons that influence changes in the population of deafblind children in general, the problems of new approaches in diagnostic studies of such cases that need also a careful neurophysiological analysis as well, and compare our data with similar studies in other countries.

W52

Encouraging the personal participation of young deafblind people in planning for the future: the value of human support and simple technology in the process

J. Fletcher, E. Boothroyd

Sense - London, UK

Content. This workshop is about the ways that young people who are deafblind/multi-sensory-impaired, approaching adulthood, can benefit from the use of both human and communication technology to be more effective participants in the discussions and decisions that will shape their future lives as adults.

Description. We will discuss and demonstrate, through the use of video of young people themselves the communication challenges faced by the young people and the professionals working with them in both expressing and understanding the hopes, interests and aspirations for future life styles. We will focus on the role of human support (intervenor and interpreters) and communication technology to support this process successfully.

Purpose.

- to stimulate discussion and comment from participants
- to provide the opportunity to share ideas about practice and outcomes for young people from a range of cultural and geographic perspectives
- to take away practical ideas that can be adapted for use in different contexts

W54

The client that can not appeal to us for help

A.van Duijnhoven¹, M. van der Meij²

¹Viataal - Sint Michielsgestel, The Netherlands; ²Centrum voor Consultatie en Expertise (CCE) – Utrecht, The Netherlands

Content. Recent collaboration between Dutch institutions specialised in caring for the deafblind to improve the situation of “hidden” deafblind patients in homes for the intellectually disabled.

Description. Research has taught us that 88% of the deafblind residing in homes for the intellectually disabled have not been (completely) diagnosed with a double-sensory problem (Evenhuis et al, 2006). One of the consequences is that they don't get the appropriate care they need.

In the Netherlands the institutions for the deafblind collaborate with the ‘Centrum voor Consultatie en Expertise’ (an independent organization concerned in behavioral problems of intellectually disabled people) to improve the situation of deafblind patients in homes for the intellectually disabled.

In this workshop we want to explain what we mean by “hidden deafblindness” and discuss the consequences. We'll explain what we have done to improve the situation of people with “hidden deafblindness”, what difficulties we came across, what we learned and how we plan to proceed in the next phase.

Purpose. The main purpose of the presentation is to discuss our experiences with “hidden deafblindness” and to share the experiences of the participants of the workshop, so we can learn from each other and improve the quality of life of these people in a more efficient way.

Questions

1. Do you recognise the problem of “hidden deafblindness” and what experience do you have with this problem?
2. What do you do to improve the quality of life of these people?
3. We are considering what to do next. Do you have any suggestions?

W55

Respite: a moment of being

F. Acunzo¹, S. La Penna², G. Lovino³, L. Mondaini⁴

¹Lega del Filo d'Oro - Napoli, Italy; ²Lega del Filo d'Oro - Roma, Italy; ³Lega del Filo d'Oro - Molfetta (BA), Italy;

⁴Lega del Filo d'Oro - Osimo (AN), Italy

“Respite”, that moment to take a break, is a strong need both for families and for the deafblind and multisensory impaired people themselves.

The presentation aims to investigate the concept of “respite”. The term can, in fact, have more than one meaning. For family members, respite may mean the need to find space for themselves where for a moment they can be relieved of their constant responsibility for providing care, especially when there is a disabled child. This partial “separation” is possible according to the degree to which the family has operated a gradual “detachment” from the child, encouraging the development of autonomy and independence. Respite therefore, for parents, seems to be a need which is closely linked to the child's growth and to their own personal growth, even in terms of their identity.

For the deafblind and multisensory impaired person, respite could be seen as an opportunity to detach from parental figures and construct other points of reference. All of this is closely linked to trust in their own abilities and also recognition of these abilities on the part of their family members.

Some concrete experiences of some of the Lega del Filo d'Oro's services will be presented. In particular, experiences of weekends organised by workers and volunteers for small user groups and meetings with families with the aim of investigating and defining the need for respite.

The aim of the workshop therefore is to stimulate a comparison of experiences and good practice, but also to show how "respite" requires ongoing personal growth and a range of concrete support systems.

What does respite mean?

What concrete support is needed?

What are the necessary conditions for using this support?

W56

Leisure Time of the Young People in the Group Home Majak n.o. in Slovakia

J. Sarisska, H. Hajdeckerova

Majak n.o. - Sady nad Torysou, Slovakia

The authors of the paper 'Leisure Time of the Young People in the Group Home Majak n.o.' will introduce the first group home for deafblind adults in Slovakia. Leisure time is a clear idea for the intact population and each intact individual has a certain attitude to it. We like our leisure time and we enjoy it. The work with young people with congenital deafblindness has shown us that the leisure time is unfamiliar for them and that their attitude to it is neutral. In the paper we would like to show projects focused on activities – painting, horseriding, canistherapy, swimming, chess and bowling. By the implementation of such projects, we want to achieve their awareness of activities that satisfy them, which they like, and to which they want to devote their time and thus develop their skills.

Questions.

1. It is possible to develop a congenital deafblind person's hobby?
2. Do the participants have any experience with congenital deafblind people finding a hobby in some artistic activities done for a long time, which they want to do without anybody having to invite them to do, e.g. 'let's paint'?

W57

Developing Cultural and Creative Activity of Deafblind Aimed at Their Socialization in the Community

S. Zarechnova

Federal State Institution „Children's House for Deafblind“ - Moscow Region, Russian Federation

Deafblind child's participation in aesthetic activity together with other children and adults expands his social experience, develops adequate interaction and communication in joint activity, ensures correction of communication disorders.

1. Play.

Organizing folklore and musical – rhythmical games, to develop social– cultural skills of interacting, to form social relations and different forms of communication.

2. Choreography.

Developing communicative skills via rhythmical – motor reactions of child, his body movements. Awareness of body abilities in fulfilling different postures, motions, gestures also means emotional awareness, ability to express feelings. Deafblind child lives in permanent stress. Dancing, music, rhythm is opportunity to remove tension.

3. Holidays.

Organizing mass interactive show programs, assisting to enrich sensual experience, expand communicative environment, develop imitation. The child transfers gained practical and emotional experience to new situation.

4. Dramatization.

This helps to develop communicative relations: children interact on stage, participate in dialogues, master communication means. Children design different life situations, establish social relations.

5. Excursions, trips, summer camps.

Children get new impressions, sensations and ideas, which become child's personal experience. Peculiarity: the child acts in real life conditions, but in specially organized educational process.

6. Reading.

The goal is to form reading interests at deafblind students. The child is an artist, an author, and a reader of books written by other students. Plot of books includes situations where children find themselves, impressions from different activities and trips.

Presentation tells about experience of socializing students in Children's House for Deafblind, using cultural – creative activity.

What is the part of parents in this activity?

W58

Developing Communication: Enabling Choice and Control

A. Telling¹, A. Snow²

¹Sense - Rotherham, UK; ²Sense - Robin Hood Wakefield, UK

The importance of communication for deafblind people to improve quality of life.

The aim of the presentation is to show the development of communication with one congenitally deafblind adult who is profoundly deaf and blind, with no formal communication, and who was new into the service. It attempts to show how communication can be empowering, giving the opportunity for an improved quality of life.

The culture within the service is person-centred, and the presentation highlights the significance of a person-centred approach when delivering services as well as how effective this approach can be when the desire is to develop motivation for communication. For a service to be person-centred, the service needed to be led by the congenitally deafblind adult, and so the development of communication was essential to empower her to have the ability to take control and make choices.

It was intended that the preferred communication mode should be 'Hand Under Hand' or 'Tactile' Sign - a method of communication described by Barbara Miles (Remarkable Conversations, 1999) as "talking and listening hands". This was not only for formal communication, but for learning about, and exploring, the environment of the deafblind person in a social capacity in order to develop language.

The presentation shows how the development of communication was conveyed: the use of video analysis to discover the meanings of both expressive and receptive understanding of some communication; a process of recording triggers for expressive communication; the value of the relationship between the deafblind person and the communicative partner, and the importance of being able to recognise emotion. Albeit limited, it shows the progression from behaviours as communication, to being expressive in, and receptive to, hand under hand sign.

The presentation concludes with the positive affect on the quality of life of the deafblind person.

Do we use positive emotion as an effective tool for measuring success?

Does a deafblind person's age affect their ability to develop communication?

W59

Marte meo – on one's own strength

F. Racksäter Nerback, J. Morehouse

Resurscenter Mo Gård AB - Hägersten, Sweden

The use of Marte Meo to develop interaction and communication skills.

The presentation will include a brief history of the Marte Meo method and its characteristics and how the method has been developed to function in various work fields. It will also include some of the ongoing research in the fields of Marte Meo and DVD-films from cases.

Marte Meo is used to identify, activate and develop skills to enable and enhance constructive interaction and development. The focus of the method is to encourage the participants to use their own strength to advance and stimulate developmental processes in daily interaction. The Marte Meo therapist captures the interaction between caretakers and caregivers on film. The film is then analysed according to checklists and then reviewed with the participants. This review is focused on the functioning interaction.

We will show how the Marte Meo therapists at Resurscenter Mo Gård AB have used the method in the work with congenital deaf blind adults and their caregivers.

Questions for discussion:

Could this be a method in your field of work?

Can you identify areas where the method can be useful for you?

W60

Use of melatonin to improve the quality of EEG recordings in deafblind subjects with cerebral damage

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¹Ospedale Murri - Fermo (AP), Italy; ²Lega del Filo d'Oro ONLUS - Osimo (AN), Italy

Both analogue and digital EEG recordings are often affected by different kinds of artefacts, such as gross body movements of the subject being examined, muscular and ocular activities, swallowing, and contractions.

The occurrence of these artefacts is therefore high in patients with poor collaboration such as those affected by cerebral palsy (CP) and mental retardation (MR) because of their lack of comprehension abilities and cognitive control over their emotions.

Considering that EEG recording is one of the most effective sources of information for studying various kinds of cerebral damage, especially epileptogenic, it is very important to develop a method to reduce the presence of these artefacts.

Usually, precautionary sedation techniques, based on administration before the EEG recording session of benzodiazepine or phenothiazine drugs, both of which have significant adverse effects, either dose-dependent (respiratory arrest) or dose-independent (dyskinesia), and many side effects (such as sleepiness or even falling asleep), are employed in order to reduce the artefacts in cerebropathic patients.

Melatonin, an indolamine, produced by the pineal gland, plays an important role in the circadian sleep-wake cycle and can be considered an agent for induction of the psycho-sensory-motor relaxation leading to sleep in normal subjects.

The aim of the present research was to evaluate the efficacy of Melatonin in the reduction of artefactual activity during EEG recording. A 10 mg. dose of Melatonin was orally administered 30 minutes before the beginning of the EEG recording.

15 subjects were examined comparing EEG recordings with the administration of Melatonin and without Melatonin. The artefacts were classified on the basis of type and duration. The percentage of artefactual activity on the overall duration of EEG recording was also measured.

The results show that Melatonin is valid for reducing the amount of artefacts in some deaf-blind subjects affected by CP and MR.

W61

Deafblindness and ageing related difficulties: diagnostics and treatment

A. Antonissen, K. de Gooijer

Viataal - Sint-Michielsgestel, the Netherlands

When deafblind people get older, the questions about their functioning can change. Besides the regular symptoms of aging, there can also exist specific questions about behaviour related to ageing. In this presentation we will present a case-study of a 45 years old man with Marshall-Stickler syndrome, who is deafblind, intellectual disabled, has an autism spectrum disorder and has epilepsy. The Diagnostic Team for the Deafblind at Viataal was asked to investigate if his evolving problems like memory loss, loss of skills and increasing challenging behaviour could be explained by the presence of early ageing or dementia.

Within this presentation we will illustrate the diagnostic process, results and further treatment of this deafblind man. The focus of this presentation will be on the importance of differential diagnostics using alternative hypotheses and the value of diagnosis by treatment.

W62

George Brown College – A Two Year Diploma Program Training Intervenors

C. Monaco, C. Ramey

George Brown College - Toronto, ON, Canada

The Canadian philosophy of intervention highlights the importance of a “total and unconditional belief in and respect for an individual who is deafblind” & “requires intervenors to have specific skills, knowledge and experiences in order to be effective in providing the best possible opportunity for people who are deafblind to access information, process it and develop communication, concepts and skills.”

Out of respect comes the commitment to ensuring that individuals who are deafblind have every opportunity to reach their true potential. Effective intervention is essential and that requires well trained intervenors.

Since 1991, George Brown College in Toronto, Canada has been educating intervenors through a 2-year (4 semester) intensive training program. The program provides students with the knowledge and skills needed to intervene with individuals with both congenital and acquired deafblindness. The importance of and opportunities for students to practice their skills with the guidance of consumers and professionals working within the field will be highlighted.

This presentation will provide insight into the various courses included in the Intervenor Program, their descriptions and outcomes. The importance of community partnerships, the impact on the community, future direction of the program and continuing education for all intervenors will be included. The impact on service providers who are now able to hire formally trained intervenors as well as our “lessons learned” will also be shared.

Educators, specialists in deafblindness, consumers, parents, intervenors, professionals and administrators will develop a better understanding and appreciation of the importance of formalized training and the benefits of outcome based curricula.

W63

Occupational activity as rehabilitation

L. Gatto, N. Marconi, C. Sartini, F. Gambini, E. Selleri, S. Stefani
Lega del Filo d'Oro ONLUS - Osimo (AN), Italy

It seems obvious that when considering those with serious multi-disabilities, the concept of manual activity has a different connotation from the normal idea of paid work.

The concept of work for these people can be seen as having a therapeutic value because it is one of the aspects on which a rehabilitation programme can be based to give them a better self-image (KNOW HOW TO DO TO KNOW HOW TO BE).

The situation of the deafblind and multisensory impaired covers a wide range on a continuum which starts from congenital deafblind people and ends with those with acquired deafblindness. In the latter case, the term 'work' may also mean real paid employment which is therefore something with a high value in a social context and is protected and encouraged by law 104.

Some years ago the Lega del Filo d'Oro took part in a European project, Horizon, on this very subject. Several people did a professional course and were given the possibility of learning a real trade and then being inserted into the world of work where in their turn, they became tutors for others.

Work situations, or rather occupational activity, are therefore inserted in a rehabilitation programme of a wider range as they then encourage the growth of other aspects, like personal autonomy, communication, motor skills and social adaptation.

Our experience has taught us that even people with very serious disabilities, if they are well prepared, can enter the world of work, both as an occupational activity and as an actual paying job.

Naturally success in learning a work task is part of the creation of a syntonic Assistant/User interaction in which the assistant is able to gradually withdraw as the User becomes capable of managing and carrying out the activity alone.

W64

Conditions for friendly relations between deafblind people and surrounding people: experience and reflections

S. Sirotkin, A. Kalyanova
All-Russia, Association of the Blind - The Children's House for the Deafblind in Russia
Moscow, Russian Federation

Development of relations between deafblind people and their partners (professionals, relatives, friends, acquaintances or new people) usually starts from business cooperation with disabled person – for accomplishment of his/her functions in daily life or his/her training (rehabilitation). Way and result of development of these relations are defined by many factors – purpose of cooperation (just service providing, care of disabled person or training, proper rehabilitation, communication), features of mutual relations, level of mutual understanding. Basically, relations between deafblind and sighted – hearing people or between deafblind people and representatives of other disability groups become one-sided (subject – object) when one side is a means for solving problems of another side.

Friendship supposes “subject – subject” type of relations, beginning and development of interpersonal communication, relations of mutual activity and personal interest, equality, mutual respect, mutual confidence, mutual compromises, a sense of mutual sympathies...

Deafblind people, particularly deafborn, signers experience great difficulties when they try to have friendly relations with sighted-hearing people or with representatives of other disability groups due to problems of communication, difference in social position and in world outlook. The main conditions of overcoming these difficulties should be the following ones:

- Fullness of communication and mutual understanding on the basis of unity of language and means of communication;
- Personal (non-pragmatic) type of relations
- Observance ethic principles and requirements by both sides

- Ability of deafblind person to be useful and interesting for his/her partner (if partner shows unselfish behaviour), to respond to help and care with at least common gratitude and positive senses.

Discussion:

- Is friendship between deafblind people and interpreters possible? Is it expedient?
- Are relations of interpersonal equality between sighted – hearing and deafblind people possible? Can sighted-hearing people be satisfied with friendly relations with disabled people? What aspects can satisfy them in friendship with the Deafblind?

Interpersonal relations as psychological and pedagogical problem:

- a) Interpersonal relations in pedagogics, special pedagogics and psychology.
- b) Interpersonal relations of people with problems of development (personal relations between people with combined problems of development) are subject to the same rules as relations between students of mainstream school. But due to lack of common and speech development interpersonal relations of disabled people are limited, specific and situational. Community of people with combined problems of development has composite system of relations where each person occupies a certain position depending on features of his/her personality, progress in studies and behaviour.

- c) Approaches to the classification of people with combined problems of development.

Description of contingent of students with combined problems of development.

Pedagogical conditions for interpersonal relations of people with combined problems of development.

The aim of our presentation is creation of pedagogical conditions for positive interpersonal relations of people with combined problems of development.

W65

Family Weekends and supporting the parents of congenitally deafblind adults who live in residential care

G. Bartlett

Sense - Birmingham, UK

Being the parent of a congenitally deafblind adult who is living away from home in residential care can cause a huge range of feelings and emotions from negative to positive. From feeling distressed, anxious and worried, to being happy, confident and able to relax and get on with your own life.

For several years I have arranged Family Weekends specifically for parents who have a congenitally deafblind son or daughter living in a residential home with Sense. The Weekends include talks and presentations from members of Sense staff, and also some deafblind people.

Overall these weekends have been very successful and given the parents the opportunity to talk to each other and share their feelings, thoughts and experiences – both good and bad.

I would like to talk about the Family Weekends and the way they have helped a lot of parents, and often improved relationships between them and the staff who support their son or daughter.

W66

The deafblind and technology

S. Fleytin

Moscow, Russian Federation

We are going to discuss the importance of the technology in the process of integration of the deafblind people in different areas of social life.

Deafblindness is one of the most severe kinds of disabilities because it, among other things, fully or partially affects the ability of the impaired person to communicate with the world around him / her. In order to compensate this loss many techniques and method are being designed, including development of the special technology. By using such technology a deafblind person can in many cases be integrated in social life, including education and job opportunities.

Unfortunately the developers and manufacturers of the such technology (in both mainstream area and in the area of the assistive technology) not always have in mind the needs of the deafblind people. There are certain models hearing aids that have elements on their surfaces that cannot be touched by finger because touching them results in significant loss of the sound quality and such elements should be replaced by sighted person.

One of the most serious problem that affects people who are deaf and blind is inability to communicate with other people who can see and hear. Today most of the leading companies in the assistive technology produced special

devices which help to eliminate this problem. Such devices have both braille and visual displays which makes communication of the deafblind people with others much easier.

Unfortunately such devices like many other pieces of the assistive technology are extremely expensive. Therefore it is necessary to persuade governments to provide means both financial and legal to facilitate obtaining such devices. The main point in this case should be that obtaining special technology for the deaf blind is no longer a mere charity. It is a real investment which will bring income in a future.

W67

Out of the comfort zone – A preliminary analysis of the psychological dynamics of letting go and still being safe – examples from climbing with cdb adults

J. Gibson¹, F. Ask Larsen²

¹SENSE Scotland - Glasgow, UK; ²Nordisk Velfærdscenter Danmark (NVC) - Dronninglund, Denmark

One of the often-argued benefits of using outdoor and adventurous activities is that they can move participants out of their comfort zone whereby learning potential may be enhanced.

Microanalysis of video footage from a congenitally deafblind man's first ever rock climb seemed to suggest changes in comfort level for both the congenitally deafblind adult and his partner. This presentation will introduce the preliminary analysis of the psychological dynamics between a congenitally deafblind adult and their partner from this footage where the psychological "comfort" of each participant is assessed using comfort zone theory from the field of outdoor education.

Some of the comfort zone theory will be presented, in particular the concepts of a secure base, comfort zone, perceived danger and actual danger will be discussed and the significance of moving in and out of different zones of comfort for both the congenitally deafblind participant and partner will be addressed with particular relation to how this might be useful for developing learning and relationships and also creating potential communication development opportunities.

A main focus point of the analyses will be to examine how the partner shifts between being a secure base for and controlling the activity of the deafblind person in relation to his own perception of danger. The hope is, that this will give us some insight in how the perceived comfort/danger of the partner influences the relation and thereby the perceived and actual freedom and safety of the deafblind person.

The relevance of this type of analysis to other activities for the congenitally deafblind and as a way of staff development will be highlighted along with models being developed to aid in the presentation of the analysis.

W68

Deafblind Individuals in the Workplace

P. Curtis, G. Gaudet, S. Copeland

Canadian Deafblind and Rubella Association-NB/PEI - Fredericton, NB, Canada

A discussion and video showing consumers with varying degrees of hearing and vision loss in work placements and how this is possible with the assistance of Intervenor. This paper will focus on the post-secondary education, training and support (Intervenor) that deafblind individuals will need in order to choose a rewarding career path that will lead to independent living, self esteem and confidence. It will demonstrate how CDBRA-NB/PEI participates in the transition planning for each consumer from high school through to job placement.

Questions:

1. At what age does CDBRA-NB/PEI begin transition planning?
2. What is the procedure used to find job placements and workplace experiences?
3. Explain the role of the Intervenor in the workplace.

W69

A New Step-by Step Manual on the van Dijk Approach to Assessment

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¹University of Utah - Salt Lake City, UT, USA; ²University Nijmegen - Haaren, The Netherlands

Content. Overview of the new manual "Child-guided Strategies for Understanding Children and Youth with Sensory Impairments and Multiple Disabilities: The van Dijk Approach to Assessment."

Description. This session will (a) provide a brief overview of the child-guided assessment techniques utilized in the van Dijk framework for assessment, (b) summarize recent research on the reliability across facilitators, (c)

introduce a new practitioner and family-friendly manual and DVD on the van Dijk framework for child-guided assessment of children who are deafblind and have multiple disabilities that has been published by the American Printing House for the Blind and, (d) provide an opportunity to view portions of an actual assessment conducted by a parent with her adolescent youth with multiple disabilities.

Purpose. For a variety of reasons, children and youth who are congenitally deafblind may be stressed during assessments and fail to deliver their best-performance. By following the lead of the student in a child-guided manner, this stress can be greatly reduced and subsequent test performance enhanced. Another effective stress-reducing technique is to have the assessment conducted by individuals with whom the child is familiar. A recent research study has demonstrated that both parents and teachers can reliably facilitate and interpret child-guided assessments when given step-by-step training. The facilitated assessments can then be videotaped for review by individuals with expertise in deafblindness, the educational team, and family members for use in designing appropriate education.

This session will introduce participants to a new manual on the van Dijk framework entitled "Child-guided Strategies for Understanding Children and Youth with Sensory Impairments and Multiple Disabilities: The van Dijk Approach to Assessment" that is illustrated by three filmed assessments on an accompanying DVD. This manual is designed to provide practitioners and family members with the detailed, step-by-step training needed to conduct a successful and effective child-guided assessment.

Questions.

1. How do audience members currently conduct assessment of children and youth who are deafblind and have multiple disabilities?
2. How can family members be effectively involved in assessment?

W70

Haptics and Haptemes – Environmental information through Touch

R. Lahtinen¹, R. Palmer²

¹The Finnish Deafblind Association - Iiris, Finland; ²Helsinki, Finland

Haptics and haptemes are from a PhD research on how dual-sensory impaired people can share environmental information interactively through touch.

The presentation will include a brief description of a longitudinal and developmental research how to adapt visual and auditive information to the body. This approach is recognised as social-haptic communication which is a form of "touch language". When the hearing and sight deteriorates communication consists of multi-systematic and adaptive methods. A person's expressive language, spoken or Sign Language, usually remains unchanged, but the methods of receiving information could change many times during a person's lifetime.

Research describes haptics in different situations enhancing sensory information and functioning also as an independent language. Haptics includes confirmation system, social quick messages, body drawing, contact to the people and the environment, guiding and sharing art experiences through movements. Haptics give the possibility to share emotional experiences and atmospheres, different hobbies and game experiences.

Haptics are made from haptemes that determines which regulations are analysed. Haptics include sharing a personal body space, meaning of touch-contact, context and using different communication channels. Communication distances are classified as exact, estimated and touch distances. This research classifies how the body can be identified into different areas such as body orientation, varied body postures, body position levels, social actions and which side of the body is used. Haptemes of movements are recognised as the direction of movements, change of directions on the body, directions between people, pressure, speed, frequency, size, length, duration, pause, change of rhythm, shape, macro and micro movements.

Social-haptic communication system is now appreciated in Scandinavian and parts of Europe. Discussions will be how different people i.e. Deafblind people, visually impaired adults and children, teachers and interpreters can learn these methods.

W71

Question formation in LIST (tactile Italian Sign Language): a case of grammaticalization?

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¹ University of Milan-Bicocca - Milano, Italy; ² Lega del Filo d'Oro - Milano, Italy; ³ Università degli Studi di Milano - Milano, Italy

Our study analyzes question formation in tactile Italian Sign Language (LISt). The general questions we are concerned with are: 1) To what extent is LISt dependent on Italian sign language (LIS)? In which areas do the two languages diverge? To what extent are Deaf-blind people sensitive to the linguistic input of interpreters?

The main focus will be on the role of the sign WHAT in LISt. LISt heavily relies on LIS for the choice of lexical material, in particular LIS and LISt signers share the same inventory of wh-pronouns. However, in LISt occurrences of WHAT are found in domains unattested in LIS. Apart from standard wh-questions, WHAT is found also in yes/no questions, disjunctive questions and it may replace or co-occur with another wh-sign.

We suggest that, in addition to its standard use, WHAT has become a generic marker for interrogative sentences. If this hypothesis is correct, this new use of WHAT in LISt is an instance of a commonly attested process in natural languages by which grammatical morphemes develop from lexical morphemes. Several factors may have contributed to this change, one being the impossibility to perceive the non-manual aspects of the sign stream. The impossibility to recover visual information from the non-manual input led tactile signers to develop an alternative strategy, by overextending the use of the pronoun WHAT. This strategy is preferred over alternative practices used by interpreters.

The presentation is organized as follows: (1) outline of our research project on LISt and of the role played by the Deaf-blind community, (2) introduction to the issue of question formation, (3) methodology and presentation of the data collected from four Italian Deaf-blind subjects, (4) analysis of the data, (5) import of this research for the Italian Deaf-blind community and for the training of interpreters and operators.

W72

Rubella: prevention and immunisation in Europe – a call for Dbl action

Joff McGill

Sense – London, UK

Statement of Content

An overview of immunisation against rubella in Europe and identifying ways Dbl and member organisations / individuals can support and promote rubella immunisation.

Main purpose of the presentation

To consider:

- Why we immunise children against diseases, and rubella in particular
- The achievements of protecting Europeans against rubella
- How we can protect against rubella
- Arguments against vaccination
- Lessons from the approach Sense has taken in promoting rubella immunisation
- A way forward for Deafblind International

Description

The session will be a presentation of some information about rubella, congenital rubella syndrome and efforts to prevent it in Europe. It will draw on lessons from Sense and other organisations who have supported and promoted rubella immunisation and it will discuss ways forward for Dbl and its members.

Questions

- What lessons can we draw from Sense and others' experience?
- What is currently happening in Europe to immunise against rubella and to promote these efforts?
- What action can Dbl and its members take to raise awareness of rubella and to promote rubella immunisation?

W73

Collaboration during turbulent times on rough seas – a multidisciplinary approach to deafblindness and mental health problems

Å. A. Endresen¹, H. Saltnes²

¹Regional Resource Centre for Deafblind, Statped Vest - Bergen, Norway; ²Oslo University Hospital - Oslo, Norway

Our presentation will focus on the collaboration between the deafblind consultant service and the psychiatric service for the deaf and deafblind.

We will share our experiences by presenting a case; a 30 year old male with congenitally deafblindness (CDB). During the last year he has been diagnosed with a bipolar disorder and an obsessive-compulsive disorder. The major challenge we face with persons with CDB is trying to understand and interpret expressions of their mental illness.

We believe that many persons with CBD have unidentified and undiagnosed psychiatric illness. This lack of identifying mental health problems deprives them the possibility to be correctly treated, both with medication and therapeutic interventions.

Part of the challenge lies in the aspects related to communication problems or lack of appropriate communication. Without an efficient language the process of examining and diagnosing mental health problems is very complicated. We had to establish new language and conversational skills to secure the diagnostic procedure and the following interventions. The interventions are based on a cognitive approach.

To give an example: We could observe that the patient showed signs of distress and was able to tell he was stressed. We hypothesized that this was related to anxiety. The client could however not tell us any details about his experiences. By collaborating with the different professionals (interpreters, adviser, psychiatrist) we managed to help the client understand the relationship between stress, palpitations, sweating, dizziness and the concept of anxiety.

The mutual cooperation between the deafblind and the psychiatric fields has broadened the perspective and has contributed to a better understanding of our client.

The presentation will include video illustrations from the therapeutic sessions.

Questions for discussion:

Adapting and understanding a cognitive behavioural approach for persons with CDB. Is it possible?

What are your reflections after our presentation?

What do we need to develop methods for identifying and diagnosing mental health problems in the congenital deafblind population?

W74

A Journey of Discovery – Exploring how to Enhance Possibilities for Meaningful and Reciprocal Communication through Touch between People who are Congenitally Deafblind and Others

M. Foster, J. Greatrex

Sense - Birmingham, UK

Content. In this ongoing research project, two Consultants on Deafblindness are working with staff, in residential homes for people who are congenitally deafblind, to enable them to become better communication partners.

Description. A Power Point presentation will illustrate the aims, the process and outcomes of the project, supported by case study evidence and DVD footage.

Purpose. This paper describes the process involved in changing ideas on communication through touch. We consider the challenges that staff and Consultants on Deafblindness encounter throughout the process and share how the insights gained have informed our approaches to staff development and enabled us to consider possible solutions for bringing about changes in current practice.

In the U.K. many people who are congenitally deafblind are currently living in residential services, supported by care staff whose access to research and training on communication is limited. Despite an acknowledgement of the potential capacity of some of the people they support, staff skills are limited and established methods and approaches have inhibited the development of expressive communication. Some people being supported in our services have not had access to a range of possibilities for communicating with others.

In this project, consultants and staff in residential services are discovering how each individual prefers to communicate and we are collaborating to interpret and find meaning in their communicative behaviours.

Practical training on tactual approaches is being provided, supported by video analysis. Through modelling and coaching techniques, we are nurturing the idea of developing social interaction that is not task-driven. We are exploring with staff, ways of engaging people who are congenitally deafblind in meaningful and sustained interaction where 'conversations' emerge. This approach recognises and builds on a person's attempts to express what they are thinking. By supporting expressive communication through touch in this way, we hope to make the negotiation of meaning possible to and give people more control over their lives.

Questions.

1. How can we ensure that staff in residential services retain and develop the skills they acquire during training?
2. Are there more effective ways of supporting staff to become better communication partners?

W75

The Importance of employment, career aspirations and self esteem to MDVI and deafblind adults

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This Presentation is to be assigned to the Key conference area of adulthood whereas the workshop focus topic is vocational training/employment.

In short: Ten European nations have developed a partnership that is occupied with the special needs of MDVI and deafblind adults and especially their lifelong learning.

The Learning Partnership and its Work Groups includes a range of expertise - such as adult educators, vocational trainers, special education teachers, university lecturers and researchers, together with parental and user organisations – and it will look at the issues involved in enabling this target group to develop their active citizenship, including routes to and forms of work, continuing education, personal and social development, and the methodologies, materials and staff training required to achieve this.

That is to say we report on the interchange between the participants all over Europe and present the results of our exchange program as an example for MDVI collaboration all over Europe. It concerns a joint movie which shall generate the common understanding of work, self-assessment and occupational outlook of multiply disabled and visually impaired citizens. By the aid of this, MDVI and deafblind have the possibility to talk about their lives in the particular institutions, their working places and their career aspirations, by themselves. This is not only a very immediate exemplification of our topic but also an adequate way of comparing the different systems of vocational training applied in the European countries participating in MDVI ACTIVE PROJECT (Multiply Disabled and Visually Impaired Citizens' Active and Creative Transition for Inclusion through Vocational-training and Education)

W76

Reflections on the emergence of an informal deafblind outdoor network

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¹Sense Scotland - Glasgow, UK; ²Andebu Døvblindesenter - Andebu, Norway; ³The Deafblindcenter Sohngaardsholmsvej - Aalborg, Denmark

This presentation outlines the history and objectives of an informal deafblind outdoor network, and presents some of the key learning from the group. It is hoped that the presentation will inspire others to join the group and help it to develop.

The group was started in 2005 by Klaus Vihelmsen from Denmark. The first meeting was held in Denmark with staff only and during this meeting initial goals and vision for the group was discussed which included:

That young and adult congenitally deafblind are given the opportunity to:

- Choose outdoor activities of interest from an individual level.
- Meet other young and adult deafblind.
- Meet different cultures.

With a vision

- That both deafblind and staff members get experiences.
- To have experiences for all the senses.
- To have experiences that are shared between the deafblind and their staff.
- To have experiences, which can make an impression, as a basis for an expression.
- That the outdoor arena should not be "prepared" for planned experiences.
- That the arena in the nature should be a frame for experiences, experiences you can relate to, see how the cooperation can develop and see how you can act.
- See how a common experience can develop and see how it is possible to act.

After the first meeting in 2005 the group began to meet annually along with our deafblind partners and we have had weeks in Norway, Scotland and Denmark. The outdoor weeks have not only achieved the goals stated above but our discussions have been an opportunity for us to share different ways of working in the outdoors and our different "outdoor cultures".

Questions

Does anyone else have similar experiences of using the outdoors in their countries?

Does anyone have experience or knowledge of different "outdoor cultures"?

Is anyone interesting in creating and joining a more formal outdoor network?

W77

Life as a Challenge: Family, Adolescence and Deafblindness

D. Sterbova

Palacký University - Olomouc, Czech Republic

The paper presents results of three years qualitative-quantitative research (2005–2008) in 11 families with congenital deafblind adolescents and young adults in the Czech Republic and Slovakia. In general these families

have the same basic needs as other families. But sometimes families with deafblind children have more problems and fewer opportunities to enhance the same quality of life in their life course cycle. The data were collected by means of questionnaires, home visits, interviews with the aim to gain relevant informations for programmes of future support to enhance good conditions of life for all members of families. Findings indicate that parents share an idea of self-fulfilment based on emotional self-centeredness severed from generativity and its concomitant responsibilities toward the children's succesful separation from their parents and future lives of children (child with disability and his/her sibling/s). Family identity, family hardeness and coherence, individual satisfaction are important factors in the family relationships. All these experiences support the good system of coping strategies and bring the challenge for their lifes.

Questions for discussion:

1. What factors have an influence on family lifes in the long transition to adulthood?
2. What factors could be helpful for succesful separation from parents?
3. Are there any distinctions that define family identity in families with deafblind member?

ACKNOWLEDGMENT: Data for this analysis were collected as a part of the state research grant "Physical activity and inactivity of inhabitants of the Czech Republic in the context of behavioral changes No: MSM 6198959221".

W78

Encouraging adaptive responses and social contact using microswitch and VOCA programmes

G. Lancioni, D. Oliva Doretta, A. Smaldone

Lega del Filo d'Oro ONLUS - Osimo (AN), Italy

This report is about a series of studies carried out at the Research Centre of the Lega del Filo d'Oro with severely and multiply disabled people using microswitch and VOCA programmes.

Microswitch programmes are interfaces with the external world which allow a disabled person to select their own favourite environmental stimulation. They are activated by very simple behaviours. Recent literature shows that microswitch can be used functionally with traditional types of behaviour (e.g. movement of the limbs), special types (e.g. small movements of the face and eyes) and vocal types (simple and complex sounds).

VOCA (Voice Output Communication Aid) is a device which a disabled person can activate by using a very simple behaviour to attract the attention of the people nearby.

The educational and practical implications of using this technology will be discussed.

W79

Formation and Transformation of Problem-oriented Life-stories – Narrative consultation to Parents of Congenitally deafblind Children and Professionals

H.E. Frölander, D. Ottoson

Resurscenter Dövblind - Gnesta, Sweden

Man is storytelling. Stories give an identity, with consequences for wellbeing, problem-solving and planning for the future. A story about a congenitally deafblind child and his/her network necessarily contains problems due to disability. Consultation normally has a focus on outcomes for the child, but interventions have a broader purpose to enhance the capacity of families and professionals to meet special needs. At the Swedish Resource centre for children with congenital deafblindness narrative consultation is offered to parents and professionals. It is a complement to consultation based on video analyses of interplay. Three or four sessions with caregivers, teachers and other invited professionals are conducted. Follow ups are organized. Verbal descriptions from the participants are categorized, give back orally and written down – like a story. It seems to have some unforeseen therapeutic effects. Theories about narratives started to influence therapy in the early 90:s. Disabilities were considered a possible theme. Specific experiences of events in the past and present and expectations for the future are brought together. Stories transform when parents and professionals express themselves and listen to each other. The child is often described as more competent. The consultant is the architect of this dialogic process, responsible for establishing an alliance and giving the problem an acceptable name. The consultant must try to understand the perspective of parents and professionals and look for the meaning for them in their stories. Narrative consultations might enhance for parents to work through traumatic events, thoughts and feelings, to participate in planning and to make informed decisions. It reduces stress and supports feeling of competence also among professionals. Most important it gives the deafblind child increased possibilities to develop and exercise influence. It would be interesting to discuss how narrative consultation can be shaped and to discuss the possible effects.

W80

Dbi Advocacy Working Group Reporting on the Status Of “Advocacy for Deafblind people” in the world B. Mason¹, G. Atieli², G. Ferioli³, L. Drescher⁴, M. Requena⁵, R. Lopez⁶, S. Munroe⁷, U. Heinemann⁸

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On 2004 the 1st of April, a historic Written Declaration (01/2004) on the rights of deafblind people was formally adopted by the European Parliament. This was the result of a long campaign by deafblind people, families and professionals in Europe. This is a good example of Advocacy.

What is the countries' understanding of the word and the concept of “Advocacy”? What are the advocacy efforts/activities undertaken in member countries? What are the political conditions of member (or potential member) countries to determine the possibility of enacting policies and guidelines? These are some of the aims of the “Dbi Advocacy Working Group”.

The “DBI Advocacy Working Group” will present the current status of their work and will propose to the participants to study and to coordinate new lines, programs and Advocacy policies.

W81

Pedagogical matrices for staff and supervisors with the purpose of surveying the development of persons with deafblindness

J. Granli, I. Axelhed

Resurscenter Mo Gård - Finspång Sweden

The presentation is directed at people who in different ways map, plan and evaluate efforts for improving the situations for persons with deafblindness. This is very often a complex situation with many factors which have to be taken in to consideration, including social interaction, attitudes, medication, degrees of impressions, activities, participation, diets, sleep and technical aids. Occasionally the conditions are changed consciously by the professionals assisting the person with deafblindness and at other times the conditions change in an unpredictable way which one has no control over. Those factors that are most important to a person's health and development can obviously only be determined hypothetically for each specific case. Resource Centre Mo Gård uses a theoretical system model to determine the different factors and analyze how they interact with one another. This presentation will describe this analytical instrument as well as give examples of how one in a concrete visual way can reveal the determining factors in a time perspective that uses these matrices. Such a material is created by the staff and supervisors together, in such a way, one creates a common language for describing what the group observing the person with deafblindness concludes. Our experience is that the group develops a greater understanding of how people and their environments function together and with this an improved ability to recognize the importance or otherwise of small changes in the persons behavioural variations or communicative expressions. This gives greater possibilities to draw conclusions from the surveillance and can assist in controlling the developmental process of both staff and supervisors.

W82

Development of communication of a young man with congenital deafblindness – presented in a longitudinal study

M. Rascher-Wolfring

Blindeninstitut - Wuerzburg, Germany

Cedric is a 22 year old young man with congenital deafblindness , with good cognitive abilities and with an additional severe physical handicap.

We could attend his development in our institution during the last 16 years, where he lives and learns with 3 other young people with deafblindness in a residential group.

Cedrics physical abilities are continuously decreasing with the years. Now in the age of 22 years he is using a wheel chair and he needs medical assistance at the daily routines.

With the presentation I will show in a longitudinal study the development of his communication and the changing of his communication during the years. The video clips of Cedric are starting in the age of 3 years and will show different kind of tactile signing. Now in the age of 22 years he is no more able to give answers with tactile signs.

The following questions will be addressed:

- which kind of possibilities for communication can we find, when tactile signing is actively no more possible?

- how important are objects of references and how can they be used?

We would like to share our experiences how to support the communicative abilities during progressive diseases.

W83

Communication and language of adult people with deaf-blindness in Bulgaria

D. Parapanov

National Association of the Deafblind in Bulgaria (NADbB) / „Helen Keller“ National Rehabilitation Centre for Persons with Deafblindness (NRCPDb) - Plovdiv, Bulgaria

Content. Review the status and development of language and communication ways

Description. We are reviewing the state of communication and language in adults with total or severe visual and hearing disabilities. They are scattered across Bulgaria, live with their families and communicate in everyday level with them through tactile signs. Good examples of tactile sign communication in Bulgaria are persons who have occurred early deafness, have excellent command of sign language, but lost vision in adulthood.

In the process of rehabilitation work with them, conducted classes and seminars, we concluded that the visual sign language should be adapted to tactile communication. We are using the experience of experts from the Union of the Deaf in Bulgaria (UDB), and Ms. Mimi Avramova - speech/language therapist and specialist of phonetic rhythmic and motorial practice. Training in a tactile sign language is doing by getting acquainted with various objects, tactile perception, dances, percussion instruments, using of tactile alphabet.

NADbB and UDB fight together, that Bulgarian state to recognize officially the Bulgarian sign language (BSL) as well as the tactile communication of deafblind people, in purpose to be introduced in the training of children with impaired hearing and children with deaf-blindness. Official recognition will help to be regulated occupation of interpreter for deaf persons and of interpreter-guide for deafblind persons. UDB through its national center, organize BSL training courses for teachers and for interpreters for deaf, including pedagogues of „Helen Keller“ NRCPDb. With the help of Ms. Avramova and UDB's specialists, we are conducting practical exercises in the deafblind rehabilitation for university students of "Special Education" subject, because in our universities, they do not receive training particularly for the deafblind.

Purpose. To introduce the audience to the problems in Bulgaria in the adaptation of sign language as tactile sign language, the status of training of teachers and interpreter-guides for deafblind persons, and efforts that NADbB make it in partnership with UDB and universities.

Questions.

1. How your national tactile sign language has been created?
2. Are the tactile sign language training courses organizing for training of deaf-blind persons, and of teachers and interpreter-guides?
3. Is there a special education system for professional training of teachers and interpreter-guides for deafblind persons?

W84

Successful Learners: Meeting the Educational Needs of Children with CHARGE Syndrome

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Children with CHARGE Syndrome present with many unique learning needs. Many children will have ongoing medical challenges throughout their lives. As they reach school age and life threatening medical needs become more stable, families are able to begin thinking about what their children can learn, how do they learn, and what needs to be in place for them to be successful students.

Students with CHARGE may continue to need access to medical staff, therefore creating a need to balance both medical and educational needs in a school environment. In addition, they begin to present with behaviors that families can often manage at home, but become concerned about what will happen in the school environment.

Professionals in the Deafblind Program at Perkins School for the Blind have educated more than 25 children with CHARGE Syndrome. As a program, we have evaluated and consulted with more than 50 children, both nationally and internationally. Many of the staff are active members in the CHARGE Syndrome Association are central members of the Education Committee. As a result of these factors, the program has developed collective expertise among educators and clinical staff. The mission of these professionals is to share what we have learned with professionals, worldwide.

This presentation will focus on the educational needs of children with CHARGE Syndrome and the unique strategies for teaching them:

1. The development of language and communication and the importance of consistent use of Total Communication
2. Successful teaching strategies across all environments (home, school, and community)
3. Successful curriculum content and how to incorporate into typical classroom environments
4. Day to day assessment questions and use of a checklist to assist in the overall management of behaviors
5. Discussion of the common learning characteristics that can be incorporated into all learning environments
6. Strategies to assist in generalizing behavior across all environments

W85

For people who lack formal language skills - Behaviours that could indicate worsening vision

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Sense - Peterborough, UK

Changes in an individual's level of vision can have an extremely significant impact on their life. For those attempting to support people who lack language skills or who may find it difficult to participate in formal vision testing, any gradual changes in that person's sight or hearing can be extremely difficult to recognise. At the same time, changes in behaviour could be incorrectly attributed to other possible causes.

The earlier that potential changes in vision can be identified, the more likely it is that appropriate support systems and strategies can be implemented in terms of improving:

- Person Centred Communication systems
- Vision Aids
- Resources and Assisted Technology
- Environmental Adaptations
- Mobility support
- Confidence and Self-esteem Issues
- Access to Information
- Staff approaches etc.

Colleagues in Sense East (UK) with differing backgrounds have compiled a checklist of numerous potential indicators that a person's vision may be worsening. We would like to discuss the general areas identified and distribute the checklist to other key professionals who may be able to make use of the checklist in its current format, or provide additional suggested indicators.

Where an individual is unable to clearly express through formal means that their vision is changing, changes in behaviour can act as useful indicators. The checklist developed could potentially enable the earlier identification of vitally important new support needs.

Questions:

- 1) Which individuals might find the checklist useful?
- 2) Is this a diagnostic tool?
- 3) Where do we go from here?

W86

Improving the quality of interactions and the role of caregiver characteristics

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In this effect study differences in improvement in careworker-client interaction, after providing a video-feedback program, are explained by careworkers' state of mind regarding their own attachment.

The workshop has a twofold focus: first to explain the principles of the CONTACT-program, developed for deafblind children and their educators. The basic thought of the program is that improvement of poor interactions will improve quality of life and prevent challenging behaviour. Using video fragments, we show how we applied CONTACT in individual video-feedback sessions with careworkers.

The second focus is to present the evaluation of the intervention, used by 12 adults and children with multiple disabilities and 85 careworkers. Results show a significant improvement in reactions of careworkers to the initiatives of their clients. Affective attunement significantly improved. An insecure state of mind regarding careworkers' own attachments was associated with stronger improvement in interactions.

This study presents an appropriate method to improve interactions between clients and careworkers. Furthermore, we present unique data of characteristics of professionals working with persons with multiple disabilities, which are assumed to be applicable to a broad group of careworkers.

Questions for discussion are:

- In the current study, interaction training was based on an interaction question formulated by careworkers. Is it necessary to teach interaction skills and sensitivity in the basic educational curriculum of careworkers?
- In which way can we use the findings on attachments of careworkers in future education?

W87

Getting in touch – Interactions between adults with congenital deafblindness and the staff who support them

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Background:

Little empirical research of interactions between support staff and adults with Congenital Deafblindness (CDB) informs an understanding of best practice with this group. The majority of research into communication options for people with deafblindness has involved children and their interactions with parents and educators. This study aims to examine what is currently happening during interactions between adults with CDB and their support staff and also to gain information about the attitudes and perspectives of the staff working with these adults.

This information will provide valuable evidence to shape training and support for staff.

Method:

Interactions between adults with CDB and their support staff were videoed on a weekly basis for a period of four months. The interactions were analysed in terms of their duration and qualities according to a coding system developed by Jones et al (1999). Staff were interviewed about their interactions with the adults with CDB that they support and these interviews were analysed for key themes.

Results:

At the time of submitting this abstract data is still being analysed and final results are not yet available. The results will be available for presentation at the conference.

Implications:

It is anticipated that the results of this study will provide evidence to shape training and support needs of staff working with adults with CDB.

This study is the first in a series of studies and the data from this study will be used to shape a follow up intervention study.

Key questions

1. What is the current nature of interactions between adults with CDB and the staff who support them?
2. What are the perceptions and attitudes of staff working with adults with CDB?
3. How do we measure quality of life for adults with CDB?

W88

Finding your identity by taking part in a network group.

A meeting between 6 women with a severe loss of sight and hearing

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Center for Døve (Center for the Deaf), Fredericia - Denmark

In this workshop we will bring into focus the importance of exchanging experiences for persons who have a severe progressive loss of sight and hearing, which means that they several times during their life have to face up to the fact, that the conditions of life have changed again. To have the power to cope with life crises and adapt to the new situation it is necessary to have the possibility to meet other people with the same problems – otherwise the process of transition will be very lonely.

"I feel sometimes very, very lonely!"

"Does somebody feel the same way as me?"

"How do other women with acquired deaf-blindness cope with their role as a wife, as a mother and as a colleague?"

Those are typical statements and questions from women with acquired deaf-blindness that the deaf-blind consultants meet within their work.

Instead of trying to give the answer ourselves we have chosen to use our qualifications as professionals to create the possibilities for deaf-blind people to meet, exchange experiences and learn from each other.

During the last year 6 younger women from all parts of Denmark – all with Usher 2 - mothers and wives, have attended a network group once a month. The group was directed by two deaf-blind consultants and the purpose was to give the women the possibility to discuss their common problems and benefit from their common experiences.

We would like to talk about and discuss some of the problems which the women broached during those meetings, f. ex the fear of being a burden for the surrounding – the change of roles in the family – communication with the children – how to be a good mother and contact with other parents.

W89

Family, school and social inclusion of deafblind and multiple sensory impaired people in Rondônia – Brazil

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The process of facilitation of the inclusion of Deafblind and Multiple Impaired students in a special school of the city of Ji-Paraná in the State of Rondônia, north region of Brazil, is being realized with the aid of MAPs and PATHs techniques. It was noted that children between 06 and 15 years old had different developmental goals according to their age, out of which none had been accomplished. A collaboration process among family, friends, professionals from school and people connected to education and health programs, and the community in general is a stimulating factor of development aiming effective inclusion of these children in their families, the neighboring communities, school and society in general. A program was launched developing work groups using the techniques of MAPs and PATHs which is already in progress. A survey of characteristics, likes, dislikes, dreams and fears has already been done and also the organization of objectives to be accomplished to get a better inclusion in the family, at school and in society. There is a lack of knowledge to realize a specific plan of activities as well as lack of guidance to the teachers of the regular schools that some of the children attend. At this stage, members of the community are getting to know the children and the characteristics of a multiple impairment and several have already scheduled a visit to the children's homes to understand better each reality so as to be able to propose actions to help in the process of inclusion in the regular school and offering specific guidance about programs to these children. Hopefully the action of such groups will help overcome the difficulties and develop the necessary knowledge.

Questions

- 1) Where is Rondônia?
- 2) What is the background of the assistance?
- 3) How many multiple impaired people are included in regular schools?

W90

Access to new technology

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People who are deafblind, because of their condition, have difficulties with communication, mobility and accessing information. As a consequence there is a real risk of isolation. New technology can be a way of reducing this risk.

The presentation illustrates the work and methods used by some of the Lega del Filo d'Oro's services to make technological aids and support for "distance communication" and information access, more accessible to the deafblind and multisensory impaired. It must be borne in mind that the tools and instruments available on the market to meet the needs of this minority, highly diversified population, are very few.

In particular, some concrete experiences which highlight the work carried out will be presented. These concern:

- evaluation (needs, abilities, environmental context, resources, etc.);
- identification and adaptation of the tools to meet the needs of the individual;

- training in use of the aid;
- monitoring and assistance.

The presentation will also show how this work requires not only the presence of a technical expert but also of a social-educational team capable of working on identified areas, and of a support network.

The aim of the workshop is to encourage comparison with similar experiences and explore the possibility of setting up a network on these matters.

How can new technology be made accessible to the deafblind?

What linking network is needed for those involved in technical development?

W91

The role of volunteers in the search for happiness

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Recreational activities and free time can contribute to the well-being of the deafblind and multisensory impaired persons. They represent personal 'space' for their global growth.

The presentation aims to highlight, using concrete experiences, the importance of recreational activities and free time, showing how they:

- allow people to demonstrate their own cognitive, social and relationship skills;
- allow people to go beyond the boundaries of their daily lives and come into contact with different places and people;
- stimulate flexibility of thought and behaviour;
- access a larger world and social network.

It also aims to show how these activities can be guaranteed and made accessible by working on some 'critical' aspects and using volunteers as support and contact people.

The choice of volunteers for the task is not only dictated by the wish to have free human resources, but by the belief that using volunteers is a valuable step towards reaching the desired objectives.

This is why the Lega del Filo d'Oro has encouraged volunteers right from the start. In recent years, it has invested even more in this resource, establishing management systems and methods of recruitment, selection, training and experience in the different activities, in order to make the volunteers more qualified.

The aim of the workshop is to illustrate this experience and encourage discussion and comparison.

How can volunteers contribute to the well-being of deafblind people?

What aspects need to be considered to make free time activities accessible?

W92

Staff and Management Development at Broder Pehr, Mo Gård Group, Sweden.

How to hold and maintain high quality in daily caretaking

G. Nylander, U. Rosendahl, I. Karlsson-Markie

Resurscenter Mo Gård AB, Broder Pehr, Hägersten - Sweden

Broder Pehr, a unit within Mo Gård Group, is located in Stockholm. The management has strategies so that members of the staff uphold influence and responsibility in the daily work. It uses work methods, recourses and follow-up-methods as well as job satisfaction and dedication among the staff, which lead to increased efficiency. To have instruments to ensure that a high level of quality is maintained is important, especially when you are taking care of people that have a hard time expressing themselves about what kind of treatment they are attending, like congenital deaf blinds. The city of Stockholm has a Quality Award that examines the units regarding systematic development, leadership, employee influence and focus on the clients. Broder Pehr was nominated to the award and received a commendation. The feedback the city gave us, high lightening the positive things and stimulating continued improvements, has led to a development for management, staff and clients.

Questions:

Do we use the right tools to maintain high quality?

How does one withhold enthusiasm among the staff in the work of congenital deaf blinds to maintain high quality?

W93

New directions in organizing work with families having children with multiple sensory and psycho-neurological developmental disorders and problem behavior

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Federal State Institution „Children’s House for Deafblind“, Sergiev Posad, Moscow Region - Russian Federation

Different forms of working with families having children with multiple disabilities and problem behavior are discussed in this presentation.

Main directions in this work:

- Exposure of families having children with multiple disabilities on the territory of Russian Federation.
- Consulting families.
- Composing individual programs and further tracing of development.
- Overcoming problem behavior in children with multiple developmental disorders:
 - a) work of “family therapists” – educators of the Children’s House;
 - b) correction of the relations which the child with multiple disabilities and problem behavior demonstrates in the family, having other children of normal development;
- Using new medical – educational technologies for correcting problem behavior in the family.

This method is aimed at developing successful relations of the child in his/her family and further socialization.

Question:

What is preferable: educating the child with multiple disabilities by the specialists in the boarding school away from the family, or consulting at home ?

This workshop has been accepted but will not be presented – replaced in the programme by W35 - Golovan

2nd US National Transition Follow-Up Study of Youth with Deafblindness

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There is general agreement that it is critical to reflect on the postschool status of our youth with disabilities especially those with varied and unique characteristics, such as those youth with deafblindness. This low incidence population represents extreme heterogeneity in the degree and variety of disability. The combination of low incidence and high variability has contributed to the problem of gathering reliable and detailed descriptive information regarding the nature of this group and their post school status. The results of the first US National Transition Follow-Up Study of Youth with Deafblindness (Petroff, 1999) revealed data that described a group of youth that were largely unemployed, receiving little specialized attention, significantly isolated from their communities and did not have the secondary education experiences known to successfully transition to an interdependent adult life.

This paper (session) reports the findings of the Second US National Follow-Up Study of Youth with Deafblindness (Petroff, 2008-09) with updated and additional information. More than a decade later, results are presented and compared to seek impressions of critical junctures and make inferences as to successful practices in the successful transition for these youth. Data is reported that has been analyzed to determine correlations between variables such as secondary education, student characteristics and current post school life thereby determining possible areas in which practice and policy may be influenced. Due to the extreme heterogeneity in this population of youth, the study gathered information through the participation of the parents and/or guardians, under the presumption that they are the most reliable informants and the notion that there is some evidence that the level of satisfaction of parents may influence outcomes for these youth.

Questions:

What are the indicators that positively influence a successful adult life for youth with deafblindness?

What is the value of conducting post-school follow-up and follow-along research of young adults with deafblindness?