



European
Down's
Syndrome
Association

NewsLetter

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Down's Syndrome: when dreams come true

Our Congress aims to start from three principles:

1. Recognition of equal rights and opportunities for people with Down's syndrome in a society that is enriched by diversity.
2. The right of everyone with Down's syndrome to receive an adequate response to their needs.
3. The specialisation or specificity in rendering services to people with Down's syndrome, which must be given by specialists in each community's normalised services.

These three principles are to serve as a meeting and reflection point for scientists, professionals, people with Down's syndrome, family members and associations who, with a universal, open, integrating and plural mentality, want to study deeply and explain the latest issues concerning Down's syndrome.

Our slogan: DOWN'S SYNDROME: WHEN DREAMS COME TRUE transmits a message of innovation and hope, emphasizing the scientific advances and therapeutic practices that are today making it a reality for people with Down's syndrome to enjoy good health and a longer life, to gain social recognition, to go to a normal school, to have a job, to live integrated in the community and, in short, to enjoy a better quality of life. In those countries where there is still so much to be done, the model to follow must be clearly borne in mind, as well as the objectives to be attained and the unconditional support from more advanced societies.

The strength and solidarity of the independent associative movement for Down's syndrome aims for consolidation in all countries, seeking public commitment and collaboration and claiming collective representation. Families, professionals and people with Down's syndrome who are working together in the associations try to adapt to present-day circumstances, to contribute new and specific solutions, to change social attitudes and to respond efficiently to the needs of people with Down's syndrome.

Affectionately,

Prof. Dr. J. PERERA
President of The VI World
Congress on Down's Syndrome

Parent Training with Parents of Down Adolescents

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Introduction

Only since the late 1960s have "projects" on parent education and parent training begun to appear with the aim of increasing parental skills in dealing with problems that might crop up daily in childrearing, in particular whether there is a "difficult" child in the family. Childrearing errors, such as reinforcing problem behaviours and ignoring adequate ones, resorting, sometimes indiscriminately and heavily, to punishment, inconsistencies, and so on, are very likely to occur and are generally recognized by the parents themselves as indicators of unsatisfactory parental "ability".

However, the need to care for the family in a systematic way is particularly apparent when situations of serious malaise occur within it. This is what happens when a family member suffers from irreversible disabilities, progressive diseases, or declining health, or when there is in the family a disabled person who, in addition to a great amount of attendance, needs also interventions as concerns care and treatment. It cannot be left unsaid that such situations produce far-reaching effects on all the family, as well as triggering off significant changes on the style and quality of life of its members. There exist clear and unchallengeable indicators of all this and they can be both "objective" and "subjective". The "objective" ones can be found in the drop in out-of-the-family activities (work, social relations with the neighbours, free time, etc.), whereas the "subjective" ones can be seen in the heightened levels of stress, the decrease in couple satisfaction and psychologic well-being, as that type of presence necessarily requires the response to "unusual and additional" care, attention, and needs. The normalization and the integration of disabled people cannot be satisfactorily carried out if families are not provided with support and social security able to solve the problems that they cannot face alone.

Thus, also as concerns the role that the family may have in the treatment and integration of disabilities we have recently been witnessing a significant progress. If until a few years ago the families and parents of the disabled were excluded from rehabilitation programmes and interventions and were mere lookers-on of what others (the "specialists") were doing, now they are given an important function also as far as treatment effectiveness is concerned. So much so that the "prejudice" by which family mem-

bers had to be excluded from the planning of treatments as they did not have "specific" knowledge and competence seems now greatly disregarded. Taking this new awareness for granted, the problem arises of the choice of support to give families and, more specifically, the kind of help to make available to parents in the management of practical everyday problems. Therefore the presence of a disabled child, besides implying a whole range of considerable economic, social, and emotional problems, needs to be anchored up to firm childrearing principles and "competences" that a parent can hardly possess if not adequately supported and "trained".

Experimentation of a Parent Training Programme with Parents of Down Adolescents

The Parent Training programme that is here presented was tested on 16 parents (8 mothers and 8 fathers) of Down adolescents included in a vocational training course. It represents an attempt at integrating various theoretical matrices: the attempt is based on learning principles and social behaviourism, but at the same time it takes into consideration indications of the systemic school and the psychopedagogic suggestions of those who, in their analysis of teaching-learning processes, focus on the need to search for specific conditions facilitating learning. The programme was articulated over thirteen sessions purposefully called "didactical" units in order to underline the psychopedagogic value of the intervention. The topics dealt with in each didactical unit are shown in Table 1.

To facilitate learning and maximize the chances of reaching the aims, the following techniques were used in each didactical unit:

- *Modeling* : in order to make quite clear the skills the participants were going to learn, learning-by imitation situations were set up in which the different members of the training group experienced in turn the role of observer, model, and "judge". In each session, the role of model was first played by the co-trainer. This technique, together with its "covert modeling" version, is widely used in the field of behaviour modification, and its efficacy is supported by a substantial experimental documentation.

- *Immediate feedbacks and positive reinforcements*: whenever there were performances functional to the rea-

First Didactical Unit:	What are inadequate behaviours?
Second Didactical Unit:	How does one learn?
Third Didactical Unit:	How to teach to do the right thing at the right time.
Fourth Didactical Unit:	When and how to gratify.
Fifth Didactical Unit:	How to teach new skills (1).
Sixth Didactical Unit:	How to teach new skills (2).
Seventh Didactical Unit:	How to observe children's behaviours.
Eighth Didactical Unit:	"Effects" of punishment.
Ninth Didactical Unit:	Alternatives to punishment.
Tenth Didactical Unit:	Couple conflicts and rearing agreements.
Eleventh Didactical Unit:	Handicap and sexuality.
Twelfth Didactical Unit:	Parents, services, and operators.
Thirteenth Didactical Unit:	Passive, aggressive, and assertive styles of communication.

ching of the aims (adequate imitation in modeling, correct execution of tests, accurate completion of homework, correct description of problem situations, etc.) both the trainer and the whole group openly expressed their approval.

- *Frequent self-assessment*: in each session self-assessment was included for a number of reasons, among which the following were considered particularly important: a) it can stir up a general discussion on the effectiveness of training; it could help to perceive with greater accuracy one's own behaviours being at the same time a kind of training to self-monitoring; b) it encourages an active and direct participation of each member in the group sessions; c) it gives the chance to get positive feedbacks.

- *Homework*: each didactical unit envisaged homework, which was tailor-made in the presence of particular difficulties. This was greatly emphasized as it was thought important in facilitating learning. Homework could actually allow: a) activation and repetition in everyday life of skills already analysed in the didactical unit, as it seems to accelerate learning processes as well as favour maintenance of learning; b) assessment of the likelihood of learning being transferred from the artificial (in which teaching - learning processes were activated) to the natural context ; c) the analysis of skills needing further investigation and improvement; d) the perduring of a learning atmosphere also in between sessions, thus avoiding the feeling that the sessions are exceptional moments in everyday life.

As concerns the evaluation of the training efficacy, measures of self-assessment, cognitive learning, and modifications in rearing attitudes were taken. Two types of assessment were used: a non-normative one (mastery criterion) and a normative one. Each didactical unit envisaged a test to assess learning: the goal was considered as reached when the parents were able

to answer at least 80% of the items of the assessment test. When the parents were not successful, they were given further explanations so that instructions on future topics might not be misunderstood because of pre-existing knowledge gaps. Figure 1 shows the assessments of goal-reaching separately for fathers and mothers.

Didactical Units	Fathers		Mothers	
	N	%	N	%
1	8	100	8	100
2	7	87	8	100
3	8	100	8	100
4	6	75	8	100
5	8	100	8	100
6	8	100	7	87
7	6	75	7	87
8	7	87	8	100
9	8	100	8	100
10	7	87	8	100
11	8	100	6	75
12	7	87	7	87
13	8	100	8	100

Fig. 1. Non-normative test on the effectiveness of the Parent Training programme. N = number, %= percentage of parents (fathers and mothers) reaching mastery criterion.

As concerns the normative evaluation modality of training efficacy, in order to obtain an initial and final measurement, Schafer and Bell's (1960) Parental Attitude Research Instrument (P.A.R.I.) was used. Figures 2 and 3 show the results of the comparison between the parents' answers at the beginning and at the end of the training.

Subtest	Pre-test		Post-test		<i>t</i>	<i>p</i>
	M	SD	M	SD		
1	14.50	1.92	19.5	3.74	-3.36	<.01
2	14.50	1.92	9.25	1.03	6.78	<.001
3	11.00	2.72	11.37	2.26	-0.29	n.s.
4	15.12	3.31	7.50	2.44	5.23	<.001
5	14.87	3.79	13.00	3.92	0.97	n.s.
6	10.25	2.18	7.25	2.71	2.43	<.05
7	11.50	4.50	9.12	2.35	1.32	n.s.
8	16.12	1.72	10.12	4.15	3.77	<.01
9	7.87	2.74	7.25	2.43	0.48	n.s.
10	9.87	1.95	8.62	2.26	1.18	n.s.
11	14.50	2.77	14.50	2.44	0.00	n.s.
12	4.87	0.99	3.87	1.55	1.53	n.s.
13	16.00	1.51	8.87	1.72	8.78	<.001
14	12.62	2.92	9.37	1.59	2.75	<.01
15	15.70	1.90	8.87	1.64	7.72	<.001
16	13.62	3.15	9.00	2.20	3.39	<.01
17	19.00	1.06	19.00	1.30	0.00	n.s.
18	9.50	1.60	12.75	3.41	-2.43	<.05
19	17.25	1.66	15.00	5.75	1.62	n.s.

Fig. 2. P.A.R.I.: Normative test on the effectiveness of the Parent Training Programme (fathers' answers).

M= mean; SD= standard deviation; *t* = *t* of Student for repeated measures; *p* = probability level. Subtests: (1) encouragement to verbalization, (2) encouragement to child's dependence, (3) mother's reclusive life, (4) "martyr" attitudes, (5) conflicts with the partner, (6) strictness, (7) irritability, (8) exclusion of external influences, (9) parents are Gods, (10) rejection of role, (11) approval of the activity, (12) rejection of communication with the child, (13) feeling of being neglected by the partner, (14) sexual repression, (15) mother's dominance, (16) intrusion in the child's thoughts, (17) camaraderie, (18) favouring development, (19) dependence on the mother.

Subtest	Pre-test		Post-test		<i>t</i>	<i>p</i>
	M	SD	M	SD		
1	16.75	3.80	18.62	3.96	-2.61	<.05
2	11.62	4.20	10.10	3.02	2.60	<.05
3	11.50	3.66	11.25	3.19	0.33	n.s.
4	15.12	2.35	11.50	3.58	2.96	<.05
5	15.60	2.56	11.37	3.99	3.07	<.01
6	17.62	2.13	8.50	2.07	7.99	<.001
7	12.00	3.16	10.87	2.74	1.38	n.s.
8	12.25	1.66	10.12	1.72	2.86	n.s.
9	10.12	1.72	8.87	1.55	-3.98	<.01
10	12.62	2.06	12.00	2.39	1.48	n.s.
11	11.75	2.71	11.87	2.69	-0.24	n.s.
12	9.75	1.98	4.87	2.23	5.11	<.001
13	9.75	1.58	9.62	2.13	0.31	n.s.
14	11.75	1.03	10.25	1.48	3.00	<.01
15	12.12	2.35	11.50	2.56	1.25	n.s.
16	8.00	1.30	7.37	1.68	1.35	n.s.
17	18.62	1.06	18.87	1.64	-0.55	n.s.
18	12.75	1.83	15.37	1.50	-3.03	<.01
19	14.75	4.33	12.87	5.66	2.31	<.05

Fig. 3. P.A.R.I.: Normative test on the effectiveness of the Parent Training Programme (mothers' answers). (See Fig. 2. for captions)

The outcome seems to differ according to the sex of the parent. The fathers showed significant differences: they decreased their tendency to "encourage the child's dependence", to take on "martyr" attitudes and to live conflictually the relationships with their partner, to hold strict childrearing attitudes, to pose as lord-and-master types of father, to reject communicating with their child and repress his/her sexuality; on the other hand, they spoke more to their child and increased

their attempts to accelerate his/her development. The mothers showed some of the fathers' decrements (encouraging dependence, martyr attitudes, strictness, sexual repression), but they also showed significant decrements at the subtests of exclusion of external influences, of feeling of being neglected by the partner, of dominance, and in intrusion. The programme was further tried on other parents, whose disabled children had different characteristics from those con-

sidered earlier, in order to check maintenance and generalization of learning (Barattini, 1995). To this end a cognitive-behavioural psycho-therapist has been, and still is, observing and recording the development of the disabled children, whereas parents' maintenance and generalization of learning were checked four months after training. The parents were asked to answer 14 multiple-choice questions about their knowledge on the principles and on the childrearing techniques they had been taught and also to express their views on a) that training experience, b) the practical implementation of the suggestions given, and c) the benefits they had noticed. To record the latter evaluations a semi-structured 25-item interview was utilised. The amount of learning that these parents had retained four months after the end of training was considerable: 66% of them gave correct answers to all the questions, 13% made 1 mistake, and the remaining 21% only 2 or 3 mistakes. Also as concerns the use of techniques and the improvements found in the children, the great majority of parents' answers were extremely encouraging. These data are significant as the problem of maintenance and generalization of learning is the ultimate goal of Parent Training programmes. What is essential is enabling families to autonomously deal with their own childrearing problems, at the same time providing, in addition to general principles and specific techniques, techniques of self-management, of self-observation, and of self-selection of goals. Thus, further validation of Parent Training programmes will be provided by the significantly decreased need for professional interventions.

The experimentation ended up as training addressing groups of parents: I think that this is important because group parent training is normally thought to have the following advantages:

- it supplies greater support to trainers, who may thus share with other colleagues the responsibility of the implementation of the training programme;
- it allows parents to give one another support, exchange experiences and opinions, discuss about the acquired knowledge, and to confront on their evaluations of the treatment under way;
- it is an opportunity for parents to realize that they are not alone in experiencing childrearing problems;
- thanks to other parents being present, it allows the general increase of confidence in the suggested procedures, as they are satisfactorily utilised by others;
- it allows to use the group as a continuous source of gratification, especially if the trainer encourages and facilitates its appearance;
- within the group, parents can find empathy and understanding and all this has positive effects on their increased confidence in their own abilities;
- last, but not least, Group Parent Trainings are more advantageous than individual ones also from an economic viewpoint; this is quite important as it would allow the services to respond to training requests from a greater number of users. Suitable and rigorously planned interventions seem to be effective as concerns the management of childrearing problems and highlight the opportunity of utilising various forms of Parent Training in the presence of a large variety of childhood and adolescence problems. At this point it's important choosing well the programme to carry out.

A first consideration focuses on the fact that treatment and integration of Down persons require numerous facilitation conditions - among them those of convergence and solid colla-

boration between professionals and family members are without a doubt particularly important and decisive. Although it may seem obvious, such agreement and convergence cannot be taken for granted, since sometimes parents' and professionals' aims seem to be so markedly different to actually bring about considerable misunderstandings and communication problems. To reduce possible "mistrust", trainers would reassure parents on the following: 1) they will not be asked to change their childrearing attitudes and their behaviours towards their child, unless they are fully convinced of the necessity of it; 2) they will be systematically told of the reasons why some childrearing techniques and modifications are proposed; 3) they will always be able to rely on the operators and on the service when in need of them, regardless of whether they have accepted the operators' suggestions; 4) changes will not be proposed or required that may be harmful to themselves or to their children, and whenever any change is proposed the consequences attached to it will be always made clear.

The "contracts" between the people in charge of the Parent Trainings and the parents must therefore be explicit, agreed upon, and as clear as possible. Frequency of meetings, schedules, modalities of management, and type of participation required of the parents must be clearly stated.

The place where the Parent Training is going to be held must also be clearly stated and accurately set up. It is not true that one place is like another; it is, in fact, important to choose pleasant surroundings (some Parent Training programmes are held in schoolrooms with desks and chairs suitable for young children, but not for adults, in areas not allowing, because of lack of space, any simulation, role-play, etc.). The importance of well-presented written material (also from a "publishing" point of view), the availability of teaching aids (blackboards, notice boards, videorecordings) that can indeed improve the quality of teaching-learning, are also aspects that must not be neglected. In fact, they contribute to convincing the parents that their training is considered "important" and "serious". If parents are asked for commitment and willingness, they cannot certainly be offered improvisation and cursoriness in return. Lastly, another fact worth considering is that, if until a few years ago it was possible only to encourage the planning and diffusion of this type of intervention, nowadays it seems important to promote debates and reflections, especially among the operators, on the criteria to use when faced with the choice of a programme to carry out. Starting from the premise that a choice will be deemed good if to the programme and training costs (both to parents and operators) will be attached reasonable advantages (for parents and children, but also for the service), I would like to put forward some suggestions to help take a decision. Before choosing a specific programme, whose suitability we might doubt at a later stage, the following points should be considered: 1) whether the goals of the programme are compatible with those of the parents who are going to benefit from it and of the operators that must implement it; 2) whether in the literature there are data supporting its effectiveness and validity; 3) whether the professional competences required for its correct use are actually held by the operators that will implement the programme; 4) whether the chosen programme, such as it is presented by its devisers is actually available in all its parts and ready for use.

Activity and first reading

Marietta Wischmeyer and Brigitte Nonn

(adapted and translated by Angela Sprotte and Monique Randel)

In the following we will be presenting a first reading scheme including both psychomotor and sensory integrative exercises using visual-auditory-tactile-kinaesthetic modalities. This scheme is the result of a "multi-track" search for "the way-in" to reading with a group of six (at that time 7-8 year old) mentally retarded pupils, several of them with Down syndrome, at the Pestalozzi School in Cologne -Porz. The form and content of our first reading scheme was, of course, influenced by discussions with colleagues, in-service training, and the relevant literature, but the decisive factor was the implementation of our shared classroom experiences.

Pedagogic Principles and Aims

By combining psychomotor elements and experiential, sensory integrative stimuli from the visual-auditive-tactile-kinaesthetic channels in a First Reading Scheme we were able to incorporate our observation of our pupils' learning strategies and enable them to access cognitive topics through activity, using all the senses.

While it was possible to employ activity and perception as in psychomotor therapy - usually in the form of a game - to facilitate learning, it is entirely thanks to intervention techniques based on sensory integration that we became aware of the importance of the visual-auditory-tactile-kinaesthetic channels for development and learning, especially for the mentally retarded children.

As our experiences with this reading method clearly demonstrate, reading lessons based on a combination of psychomotor and sensory integrative stimuli enable the pupils to access written language more easily.

My colleague, Mrs Nonn, and I have used this method of teaching reading for five years, and are now in a position to say that, quite apart from the pupils' varying degrees of increased reading competence, the most important results are their relaxed approach to learning, their growing self-confidence, sense of identity and self-esteem.

These can also be considered the most important aims of this reading method.

A Sensorimotor Learning Sequence - Introducing Keywords in a Reading Scheme for Mentally Retarded Children

After extensive prereading activities and an "experimental phase", the following learning sequence was developed for our pupils. Irrespective of the first reader, it seemed to be essential to use the exercises described below - especially when introducing and working on a new keyword. The steps in the learning sequence are not in a hierarchical order, though they have been carefully graded.

- presentation of characters in the reader (e.g. by means of a hand puppet / rôle play)
- presentation of the relevant keywords/logograms (extensive, visual presentation)
- introduction of signing of sounds (the combination of the visual and auditory presentation of a keyword with „descriptive signing“ reduces the abstract content of the phoneme analysis and synthesis of the word.)
- visual presentation of the keyword and a picture of the character from the reader (a simultaneous logographic presentation)
- Comprehension on a gross motor level of the keyword and the letters it is composed of (e.g. by walking round the keyword; by tracing the shape of the keyword with balls, toy cars, roller skates; by jumping over the keyword in a game of hopscotch)
- visual discrimination of the whole word (e.g. by hitting the right word on the board with a soft cushion, so distinguishing it from the other word shapes/logograms)
- tactile comprehension of the whole word and its letters (e.g. running hands over letters made of various materials, fishing letters from the word out of a container filled with sand)
- visual discrimination of the letters in the word (e.g. by throwing balls at the board or by circling letters on a worksheet)
- visual discrimination of letters by allocating them to their place in the whole word (e.g. working with wooden letters of the alphabet as a final exercise in the analytic-synthetic phase.)
- auditory discrimination of the individual sounds in a whole word (e.g. identifying initial sounds by selecting pictures of objects with the same initial sound as the keyword - this can also be practised in a game, rolling words along a scoreboard from the picture box to the keyword box)
- practising motor writing skills (encouraging the use of the written language; a progression of large scale tracing and tactile exercises - from gross

to fine motor skills)

- sensory-perceptual exercises integrating the keyword in a pictorial context.
(e.g. setting up "letterboxes" to which the students have to deliver the „mail“)
- first practice in alphabetic reading, after acquiring a certain logographic competence
(e.g. with "alphabet dolls", toilet rolls which the students themselves have painted or decorated, with the small and capital form of a grapheme on both front and back; these letters then "look for each other" until they are able to "link up".)

These reading strategies, based primarily on psychomotor skills, were used in varying combinations to familiarise the students with the keywords. Once this learning process was completed, the familiar keyword reoccurred at the various *learning stations*. (This should be understood as a chronologically dynamic process).

This brings us to the second stage of our reading scheme: reading practice with well-known keywords/logograms at so-called learning stations:

Learning stations for sensory integrative activities in a classroom setting when beginning reading with mentally retarded children

The idea of promoting sensory integration, based on neurophysiological and developmental findings, was developed in the seventies by the American psychologist and occupational therapist, JEAN AYRES. This approach was originally used in occupational therapy to treat children with learning difficulties. JEAN AYRES defines sensory integration as the ".....process of ordering and processing sensory impressions (sensory inputs), to enable the brain to produce both an acceptable physical response and equally appropriate perceptions, emotional responses, and thoughts. Sensory integration sorts, files, and synthesises all the sensory impressions of an individual into a complete, comprehensive function of the brain." (AYRES, 1984, p. 37, Translation from German text)

AYRES sees defective sensory integration among other things as a failure of the brain "to process and file sensory impulses, in such a way that the individual is able to acquire relevant and exact information about himself and his surroundings" (AYRES, 1984, p. 71). WALTRAUT and WILFRIED DOERING consider problems of integration to be the consequence of various processes. They maintain that physiological as well as psychiatric/emotional disturbances can be hidden behind perceptual difficulties.

When looking at it from the point of view of developmental psychology, JEAN AYRES points to the "fundamental" importance of achievements in sensory integration for a person's development. During pregnancy a baby has his/her first sensory experiences via the vestibular,

tactile and proprioceptive senses. Even before an unborn child can receive information via an auditory or visual channel, s/he gains first impressions about him/herself through the vestibular, tactile, sensibility senses. The development of these three senses forms the basis for the development of higher cognitive functions. Correspondingly a therapeutic approach through sensory integration aimed at stabilising the basis of a child's development, will, first and foremost, attempt to stimulate these sensory systems.

Addressing these senses when teaching cognitive content to mentally retarded pupils adds a pedagogic component to an originally therapeutic approach, and at the same time takes into account the basal, perceptual interests of our students, especially when confronted with more abstract topics.

This sensory approach enables them to "keep their heads clear" for the learning topics surrounding them.

Five years ago, my colleague and I developed learning stations where the students could work with logograms to put this approach into practice

Presentation and Description of the Learning Stations

Trampoline

Word or picture cards are laid out in a radial pattern round a mini-trampoline. After brief relaxation exercises on the trampoline the student reads every word. After this the student jumps up and down rhythmically on the trampoline, while the words he has just read are called out to him one after the other. While jumping round and round, the student looks for the word and then jumps down onto it, calling out the word as he does so. This exercise continues until all the words have been jumped on. Then it can be varied and repeated.

This exercise primarily addresses balance and proprioception. In some pupils the rhythmical movement and speaking aloud also stimulate speech and articulation.

Reading with Jars

This station comprises a space hopper, screwtop jars, paper, a pencil, counters with a letter of the alphabet on each and two tables at right angles to each other.

The student sits on the space hopper, chooses a jar, unscrews it, tips out the counters it contains and uses them to form a word he has already learnt. Then he turns and hops with the ball to the other table and writes down the word he has just formed and read.

Depending on the student's level this exercise can be varied, e.g. words can be copied or used to form sentences.

Here again balance and proprioception are primarily involved.

Pistachio Shells on a Scooter Board

A box of pistachio shells is placed on the front edge of a 1 by 1 1/2 m scooterboard (a low balancing board used in physiotherapy). Hidden among the shells are 10-20 metal bottle tops, each with a letter of the alphabet written inside.

On a wooden board by the box are word cards.

The student sits cross-legged on the scooterboard in front of the box of shells and looks for the bottle tops and allocates each bottle top letter to the word card with the corresponding initial letter.

Here it is the vestibular and tactile senses which are predominantly addressed.

Washing line!

A washing line about 3m long is stretched between two ladders; at intervals along the line pictures of the known keywords are hanged; under the ladders are two baskets - one is filled with pegs - the other with word cards that match the pictures on the line.

The student sits cross-legged on a scooterboard, rolls along under the washing line, pegging a word card on each picture.

It addresses mainly the vestibular sense and fine motor skills.

Fishing!

A box of whole word cards with paper clips in them and a one-legged stool standing next to it. In front of the stool there is a wooden board covered with picture cards of the keywords. A fishing rod fitted with a magnet is ready for use.

The student sits on the "wobbly stool" (senior students!) and fishes out a word shape card (magnet on paperclip) and transfers it to the right picture card.

It activates vestibular sense and hand-eye co-ordination.

Look and Spin

A twister is placed on a felt carpet in the reading corner surrounded by whole word cards. Next to it is a tray of single letters.

The student sits cross-legged on the twister with the tray of letters on his lap. As he spins round he allocates the single letters to the word shapes until there are two of each word. It activates the vestibular sense and visual-discriminatory skills.

Ball Sack and Metal Strips!

A 2 by 1 1/2 m sack (duvet cover stitched along the top) filled with small plastic balls is put on the floor; next to it is a tray of oblong metal strips with logograms glued to them. The student lies on his back on the sack; he is shown and reads the whole words; he can then choose on which part of his body the metal strip should be placed.

It stimulates the tactile and proprioceptive senses.

Throw and Peg!

A one-legged stool, a felt board and a wooden dice with whole words on each face. In front of the stool there are "chains of word," (words written in a horizontal order on long white cards) and a tray of pegs.

The student, sitting on a wobbly stool, throws a word and pegs the matching one on the word chain.

It trains the vestibular sense and fine motor skills

Reflections

After teaching our students according to this method for five years, one boy reads fluently and understands all unknown texts, a girl reads and comprehends shorter unknown texts, another boy is becoming increasingly confident in making sense of simple sound and grapheme sequences, a second girl is starting to synthesise, finally another girl while unable to do alphabetical reading, is able to recognise whole words and greatly enjoys working with letters.

There has been a decisive improvement for all of us in the classroom atmosphere. Setting up the learning stations twice a week, of course requires a lot of work, but once this is done, an atmosphere of quiet concentration and harmony often fills the classroom because the "whole person" is addressed.

Holistic Aspects and Interdisciplinary Links

Many mentally retarded children - especially children with Down syndrome - appear to have deficits in sensory integration, which interfere with cognitive learning. Because many of them are unsure of themselves, have tactile over-sensitivity, frequently have deficits in co-ordination and balance, they are unable to explore their surroundings appropriately. Instead, they are preoccupied with themselves and compensating for their perceived problems. One pupil constantly turned objects round and round and followed them with his eyes. When he was allowed to do a certain amount of spinning on the twister during the reading lessons at the learning stations, his attention could be drawn to the logograms around him. While spinning around he was suddenly able to concentrate for long periods of time. This and many other examples demonstrate how students find dealing with cognitive exercises much easier if they are simultaneously approached through the visual-auditory-tactile-kinesthetic channels.

During the teaching sequences at the learning station visitors were impressed by the harmonious and tranquil atmosphere. Could this perhaps also be attributed to the "holistic approach" which combines basal sensory experiences with cognitive elements? (Cf. EGGERT, 1994. Chapter 1.3.1)

Adding pedagogic aspects to therapeutic strategies in classroom teaching and aims offers the student a wider range of transfer experiences. This leads to an increased effectiveness of an originally therapeutic concept. (This has long been adopted for psychomotor therapy)

This teaching method calls for increased interdisciplinary communication between colleagues. At our school, the Pestalozzi School in Cologne-Porz, we started an optional course for 12 teenagers from two different classes, which met one afternoon a week to gather sensory integrative experience in learning numbers.

For four years a team consisting of a subject teacher, a physiotherapist, a special education teacher and a motor skills therapist took turns to teach the group. It was a marvellous experience and gave each of us a lot of new ideas.

The combination of psychomotor exercises with activities expressly aimed at sensory integration in one lesson - often within a single step - indicates how closely the stimuli are interlinked, corresponding to the in- and outside world of

a mentally retarded person and allowing him to structure his own learning capacity.

References on request

Down Syndrome and Odontostomatology today

Enrico Calcagno

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Over the last few years the concept of "special care of dentistry" has greatly improved the relationship between doctor and patient, especially when this latter is affected by a chromosomal disorder like trisomy 21. The modern medical concepts have stimulated and facilitated the approach towards this patient who generally shows a grateful, loving and collaborative attitude towards his dentist. For his part, the dentist does not see in his patient only a disease, but recognizes a person affected by a congenital syndrome with known clinical features and for which there are specific therapeutic protocols. For these reasons, polymorphic changes of trisomy 21 no longer cause in the patient feeling of fear or anxiety towards the dentist who, in past years, felt to be facing something obscure, undefined. The improved knowledge of systemic diseases and the improvement of cardiorespiratory therapies have contributed to make the Down child confident, from a very early age, towards dental therapy of the orofacial zone aimed at obtaining good cosmetic and functional results. A correct relationship between dentist and Down child is the essential basis of the future quality of the oral cavity conditions. In other words, it is important to make friends with the patient to introduce him/her to the classic instruments of dental therapy, which should be proposed as toys to enter his imagination. If this happens, the child's collaboration will be complete and the patient will often mention his playful relationship with the dentist. Preventive measures should be taken already in the first months of life, underlining the role of the dentist in the child's psychomotor and relational development by coordinating his efforts with those of both parents and other specialists in the medical and teaching fields. For this reason, the first visits are extremely important also to inform the parents on all the procedures to be performed with their collaboration.

Interocclusal recording for Castillo Morales palatal bite, together with therapy explanations to the parents in the presence of oral physiotherapists, is the first essential step for the correction of orofacial muscular dysfunction to improve deglutition, respiration, growth of maxillary bones (especially superior) and of alveolo-dental arches. Good cosmetic results can also be obtained in the mid facial portion, thus contributing to a better psychological identity of the future child and adult. Palatal bite treatment is maintained in the first years of childhood with the constant collaboration of physiotherapists to prepare the child for orthodontic therapy. During these years, the concept of oral hygiene is stressed, thanks to the figure of the hygienist who, in occasion of each visit, illustrates kindly but resolutely the most effective brushing and fluoroprophylaxis techniques to face the negative effects of the bacterial plaque. This is the best prevention against the high incidence of periodontal disease appearing during adult age with the formation of tartar, diffuse gingivitis and tooth mobility. An adequate education and oral hygiene are therefore essential, and the parents should be well aware of the preventive measures needed, especially when their child is affected by a severe cardiopathy. In conclusion, the patient with trisomy 21 should become as collaborative as possible thanks to his familiarity with dental therapy and instruments. The dentist should consider this patient like any other patient, even if requiring special care. The confidence and esteem that the dentist will be able to obtain from his "friend" will make subsequent controls easier and the good conditions of the oral cavity more durable.

6th World Congress on Down's Syndrome Madrid (Spain) 23-26 October 1997

CONFERENCES AND PLENARY MEETINGS

THURSDAY, 23rd OCTOBER 1997

Pierre Marie Sinet. (France)

Towards the identification of the genes involved in the pathogenesis of Down's syndrome.

Alberto Rasore-Quartino. (Italy)

The present state of medical aspects in Down's syndrome.

Susan Buckley. (United Kingdom)

Promoting the development of children with Down's syndrome: the practical implications of recent psychological research.

Charles J. Epstein. (U.S.A.)

The future of biological research on Down's syndrome.

FRIDAY, 24th OCTOBER 1997

Robert Hodapp. (U.S.A.)

What do we know about intellectual development in individuals with Down's syndrome?

Lynn Nadel. (U.S.A.)

Learning and memory in Down's syndrome.

Henry M. Wisniewski. (U.S.A.)

Down's syndrome and Alzheimer's disease.

Jean A. Rondal. (Belgium)

Language in Down's syndrome: current perspectives.

Marjorie Beeghly. (U.S.A.)

Temperament in children with Down's syndrome.

Michael J. Guralnick. (U.S.A.)

The effectiveness of early intervention for children with Down's syndrome.

SATURDAY, 25th OCTOBER 1997

Albert Fortuny. (Spain)

What can we discover with prenatal diagnosis?

Carmen Garcia Pastor. (Spain)

Integration: a committed form of working in school.

Jan-Erik Wänn. (Sweden)

Assistive technology compensating people with Down's syndrome.

J. Perera. (Spain)

People with Down's syndrome's autonomy and life quality.

Don C. Van Dyke. (U.S.A.)

Issues of sexuality in Down's syndrome.

Enrico Montobbio. (Italy)

The working role, a social citizenship for the adult with Down's syndrome.

SUNDAY, 26th OCTOBER 1997

J. Perera. International Down Syndrome Federation (FISD).

Keys to the Down's syndrome associative movement in the world.

PRESENTATION OF NATIONAL FEDERATIONS

The day-to-day struggle: realities and projects.

LECTURERS:

U.S.A. - Myra Madnich. National Down Syndrome Society (NDSS).

CANADA - Josephine Mills. Down Syndrome Research Foundation.

EUROPE - Richard Bonjean. European Down Syndrome Association (EDSA) (Belgium).

LATIN AMERICA - Magdalena N. Mendoça. Federação Brasileira das Associações de Síndrome de Down (Brazil).

AFRICA - Marie Schoeman. Down Syndrome Association of South Africa.

JAPAN - Yoshikatsu Morooka. Japan Down Syndrome Network.

MIDDLE EAST - Saud Al Malaq. The Saudi Society for Education and Rehabilitation-Down Syndrome (Saudi Arabia).

SPAIN - Francisco Astudillo. Federación Española de Instituciones para el Síndrome de Down (FEISD).

ASIA - PACIFIC - Penny Roberston. Down Syndrome Federation of Asia-Pacific.

PRESENTATION OF FISD

LECTURER: Josephine Mills. International Down Syndrome Federation (Canada).

CONGRESS CLOSING CEREMONY

- Presentation of Document-Conclusions.

- Presentation of 7th World Congress in Sydney, AUSTRALIA.

- Official closing ceremony.

WORKSHOPS: PARALLEL SESSIONS

THURSDAY, 23rd OCTOBER 1997

HEART PROBLEMS

A) Heart problems; B) Heart surgery; C) Down's Heart Group

FAMILY

A) The family: restraint or stimulus for integration; B) Brothers, sisters, grandparents, uncles and aunts; C) Support for the family

INTEGRATION IN SCHOOL

A) Evaluation of the integration process; B) Strategies for effective inclusion; C) Support in the classroom

FACING THE FUTURE

A) Becoming aware of the difference; B) What is Down's syndrome for me?; C) The way towards independence

WHEN A CHILD IS BORN WITH DOWN'S SYNDROME

A) Announcing the diagnosis; B) Proposals to new parents; C) Crisis in the couple as a result of having a child with Down's syndrome

IMMUNOLOGICAL AND HORMONAL PROBLEMS

A) Growth hormone; B) Thyroid; C) Immunology and infections

EMPLOYMENT

A) Professional guidance and training for work; B) Employment: adaptation and performance; C) Social integration through work

INCLUSION AT DIFFERENT EDUCATIONAL LEVELS

A) Primary integration; B) Secondary integration; C) University integration

QUALITY OF LIFE

A) Decision-taking; B) Living as a couple; C) Social image of the person with Down's syndrome

EARLY INTERVENTION

A) Maturing and abnormal and normal development of the child with Down's syndrome; B) The role of the family and environment in early intervention; C) Areas and models of intervention

FRIDAY, 24th OCTOBER 1997

OTHER MEDICAL MATTERS

A) Celiac disease; B) Dental care; C) Sleep apnea and pulmonary hypertension

AFFECTIVE AND SEXUAL RELATIONS

A) Affective and sexual education; B) Points of view of parents, brothers and sisters; C) Personal testimonies

ASPECTS OF INCLUSION IN SCHOOL

EXPERIENCES OF AN INDEPENDENT LIFE

A) What independence means: self-advocacy; B) Housekeeping; C) Relation with the environment: self-advocacy

IMPLANTATION AND DEVELOPMENT OF LANGUAGE

A) Prelinguistic bases of language; B) Speech development; C) Adult language

CONTROVERSIAL THERAPIES

A) Medical therapies; B) Repair and plastic surgery; C) Physical therapies

LEARNING AT SCHOOL

A) How children with Down's syndrome learn; B) What a child with Down's syndrome can learn; C) Adapting curriculums

SPORT - PASTIME - FREE TIME

A) Sport; B) Pastime; C) Free time

COGNITIVE PROCESSES

PRACTICAL APPLICATIONS OF GENETIC RESEARCH ON DOWN'S SYNDROME

A) New genes in Down's syndrome; B) Genotype-phenotype relation - what do we know?; C) Animal models of Down's syndrome: objectives and results

SATURDAY, 25th OCTOBER 1997

ETHICS AND DOWN'S SYNDROME

A) Genetic therapies; B) Prenatal diagnosis; C) Sterilisation

READING - WRITING - MATHEMATICS

A) Reading - written language; B) Writing; C) Mathematics

LEGAL ASPECTS

A) Adoption; B) Incapacity and guardianship; C) Testamentary aspects

PSYCHOLOGY OF DOWN'S SYNDROME

A) Memory and learning; B) Personality and behaviour; C) Other aspects

MOTOR DEVELOPMENT

A) Specific motor pathology of Down's syndrome; B) Rehabilitating treatments; C) Psychomotor aspects of Down's syndrome

PSYCHIATRY IN DOWN'S SYNDROME

A) Dilemmas of psychiatric diagnosis in persons with Down's syndrome; B) Standard evaluation of psychiatric disorders in mental retardation; C) Mental health needs of people with Down's syndrome; D) Pharmacological treatment of psychiatric disorders in Down's syndrome

NEW TECHNOLOGIES APPLIED IN THE CLASSROOM

A) Interface designs; B) Reading programmes; C) Educational uses of Internet

STAGES OF LIFE

A) From baby to childhood; B) The adolescent crisis in Down's syndrome; C) Ageing

NEUROLOGICAL AND SENSORIAL ASPECTS

A) How to improve the sight; B) Hearing problems; C) Neurological and neuro-pathological aspects

VARIOUS MATTERS

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