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**FEATURING:  
Calendar  
of  
International  
Conferences,  
2000**

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CONTENTS

|  |    |
|--|----|
| <b>Editorial Note</b><br>Roger A. Fazzino  | 1  |
| <b>Estimation of the Level of Functioning of Disabled<br/>Children's Parents as a Result of the Application of<br/>Educative-Supportive Influence</b><br>Malgorzata Sekulowicz, Ph.D | 3  |
| <b>Special Education: Empowerment Through Education</b><br>Anupriya Chadha   | 17 |
| <b>Seventh Biennial Conference of the International<br/>Association of Special Education</b>   | 23 |
| <b>Hunter's Syndrome: Description and Educational<br/>Considerations</b><br>Teresa Naggs   | 25 |
| <b>Strategies for the Content Areas: Strategic Instruction<br/>in the Content Areas using Mnemonics</b><br>Karen A. Sealander, Ace Cossairt,<br>Greg Prater, Richard A. Shade        | 41 |
| <b>Calendar of International Conferences</b>   | 51 |

## EDITORIAL NOTE

This edition of the *Journal of the International Association of Special Education* (Vol. 2, No. 2) was delayed due to late submission of manuscripts from members living in more remote areas of the world. In order to publish high quality papers time was needed for revision and, in some cases, additional research. The Editors are please to announce that the Summer 1999 edition (Vol. 3, No. 1) is currently with the publisher and should be mailed shortly.

The inside cover of this edition lists the editors who have given the time and expertise necessary to insure quality. This group of professionals represents teachers, professors, psychologists and administrators actively working in the field of Special Education. Any IASE member wishing to join this group and willing to commit the time necessary to do the job well should submit a letter of intent and a resume to me. All editors serve in a non-paid, voluntary capacity.

A new feature of the *Journal* is the inclusion of a calendar of international conferences related to the field of Special Education. The Editors hope this new feature will help IASE members in finding international conferences of interest. Please let us know your thoughts regarding this new feature.

Classroom teachers are the keys to successful education practices throughout the world. Teachers do so many wonderful things that directly impact the children we serve. It is with this in mind that articles are now being sought for a future edition of the *Journal*. Finally, the Seventh Biennial International Conference of the IASE is currently screening proposals for the 2001 conference in Warsaw, Poland. We are confident that excellent articles and papers from this conference will be represented in future editions of the *Journal*.

Roger A. Fazzone, Ed.D.  
Editor

**ESTIMATION OF THE LEVEL OF FUNCTIONING  
OF DISABLED CHILDREN'S PARENTS AS A RESULT OF  
THE APPLICATION OF EDUCATIVE-SUPPORTIVE INFLUENCE**

**MALGORZATA SEKULOWICZ, PH.D.**

**ABSTRACT**

The paper is dedicated to the analysis of the functioning of disabled children's parents in the presence of problems that consider many essential factors. In the theoretical portion of the study, the author analyzes the influence of types of issues: parent's age, child's age, place of living (town or village), the level of social support and other ways of parental coping. In the research portion, readers will be presented the results of research on the level of fear and the level of social support in conjunction with the role of educative-support therapy. The research was conducted in Poland, specifically in Lower Silesia.

**A Handicapped Child in a Family as a Critical Life Occurrence**

Giving birth to a handicapped child causes many changes in a family's life. These changes concern all the members of the family, but these changes are felt most intensely by mothers because they must cope with the care and upbringing of a child in these completely changed circumstances. The presence of a handicapped child is an important source of stress for a mother and her family (Bebko, 1987). The disease of a child can be considered in the category of a critical life occurrence (Faber, 1975) as it has a direct influence on functioning of mothers and the whole family. The stress caused by the presence of a handicapped child in a family makes family members learn to cope with this difficult situation. Everyday life with a handicapped child needs many sacrifices. Mothers complain that almost everyday, they meet a problem that influences the family in a negative way. In a situation when problems of everyday life overlap on traumatic life occurrences, such as having a handicapped child, we can expect the effect of "sea waves" or problems overlapping to appear. Such a situation can lead to the condition of complete helplessness and being unable to deal with the problem.

**The Burnt-Out Syndrome in Parents of Handicapped Children as a Result of Experiencing Long-lasting Stress**

In 1979, Ruth Sullivan presented the conception of the burnt-out syndrome that can be observed in parents of mentally handicapped children. The author characterized it as physical and/or psychological exhaustion coming into being as a result of long-lasting care of a handicapped child. Care and upbringing of a handicapped child causes the feeling of loneliness, isolation and also helplessness taken up by parents, which in turn can lead one to lose life powers.

shock, also called by the author the critical period or period of emotional shock, appears directly after parents learn about the handicap of their child. The author characterizes this period as especially difficult for parents when their experiences are dominated by despair, regret or a sense of wrong and helplessness (Obuchowska, 1991). Parents describe this period in their lives as a series of pain and suffering. Typical symptoms and emotional reactions such as: lowered mood, crying, aggressiveness and severe nervous states can be noticed in them. It is typical that the family experiences many difficult moments, ill feelings toward one another and aggression. The author suggested that it is this period when parents need the help and support of others the most.

After the period of shock comes the period of emotional crisis, which is also called the period of despair and depression. Parents still experience strong emotions even though their progress is not so tempestuous as during the period of shock. The feelings of repulsion toward life, loneliness and helplessness dominate in parents. The future of a child in the parents' eyes is very pessimistic. Altogether with the increase of problems, the scale of conflicts and arguments between spouses grows. In this stage of crisis, fathers can move away from the family's problems. They stop being involved in family matters and affairs and they look for solutions in alcohol and become more involved in their work. In many cases, they leave their families. The next stage in adaptation, according to Obuchowska (1991) is the period of seeming adjustment to the situation. It is characterized by using different defense mechanisms that deform the reality and paint an abnormal picture of a child. In the most common situation, they do not accept the fact that their child is handicapped, admitting that a child is lazy, stubborn or malicious (Borzyszkowska, 1979). Not believing the diagnosis of professionals, parents make long and expensive travels in search of a better diagnosis. It rarely is different from the first stage (Galkowski, 1995). Parents who accepted the diagnosis use other defense mechanisms. There is, among others, unjustified belief in the possibility of a child's recovery. When the conventional methods have no results, parents turn to unconventional methods that are usually very expensive. Moreover, parents use other defense mechanisms such as, looking for people who would be responsible for their child's handicap. It happens that they blame medical staff, doctors and nurses, who in the parent's opinion, did not work well enough. They see these professionals at fault for the child's illness (Obuchowska, 1991). Many people think that Providence is responsible for the handicap, saying, "That's God's plan". These people usually come from rural areas and small towns (Gray, 1994; Bristol, 1991). The period of seeming adjustment can last very long. If parents admit that they have used up all the possibilities to help their children, then they give up trying. They agree with the fact that there is no chance to improve their child's health. They give in to low spirits and become apathetic. They resign all the therapeutic assistance and if they have another healthy child, they focus all their attention to ensure him or her the best

and on how severe the child's handicap. Some authors name two groups of people who care in the network of support. In the first group, we can find the professionals: doctors, psychologists, educators, social workers and government clerks who work under the plan. The second group is the people who are not professionally connected with helping: family, neighbors, friends, parents who are assembled in different forms. The support most often sought is financial, psychological and informational or service support (Valentine, 1992). Factor and others (1991) recognize another very important form of support. There is a replacement care that is especially wanted by mothers of handicapped children. In his opinion, the care of an autistic child is much more difficult than the care for other handicapped children. Thus, after-hours breaks have a crucial meaning for mothers in the process of coping. This special form of support is turning to God with the problems (Bristol, 1991). God is the only one on which they can entrust with their problems and worries, the only one on which to rely. There is a great need for help; therefore, several government programs, foundations and associations come into being. Their aim is to help parents and handicapped children. Rehabilitation camps have an important role in helping parents. Parents go to the camps with their handicapped children where there are also therapists, psychologists and special educators. Parents have the opportunity to participate in educational and supportive training there.

## METHODOLOGY OF OWN RESEARCH

### Defining the research problem:

Based on the analysis of the hitherto research on a family of a handicapped child (Galkowski, 1995), we can say that parents and particularly mothers cope quite well with problems coming from the upbringing and care of their children. Therefore, the main aim of the research presented below was the evaluation of the justification of educational and supportive training for parents and the evaluation of using strategies of coping when taking into account the level of fear, as well as the estimation of sought and received social support. The result of the research can serve as a specific written program of therapeutic assistance for mothers, children and all members of the family. In connection with the above research, I put forth the following research problem: What is the influence of educational and supportive training on ways of coping by parents of handicapped children? This problem raised the following more specific problems:

1. Are there any differences in the ways of coping before and after training?
2. Is there any change in powers or intensity of satisfaction from the received social support and whether there is any change in the number of people who give social support?

fear or state and subscale S-2 serves to measure fear as the feature.

The instrument to measure the variable of social support is the questionnaire SSQSR by Sarason and Zalewski; Obloj and Skuza made a Polish version. There are six questions describing difficult situations in people's lives. An examined person gives the answers and shows the network of people with whom he or she expects to receive support. S1 describes the level of satisfaction from received support and S2 (measured in a scale from 1-6). The indicator of the variable of social support is the size of the network of support and the intensity of satisfaction from the received support. Statgraf ICS Plus ver. 6.0 and Statistica rel. 5.1 were used to data analysis.

### **The Progress and Organization of the Research**

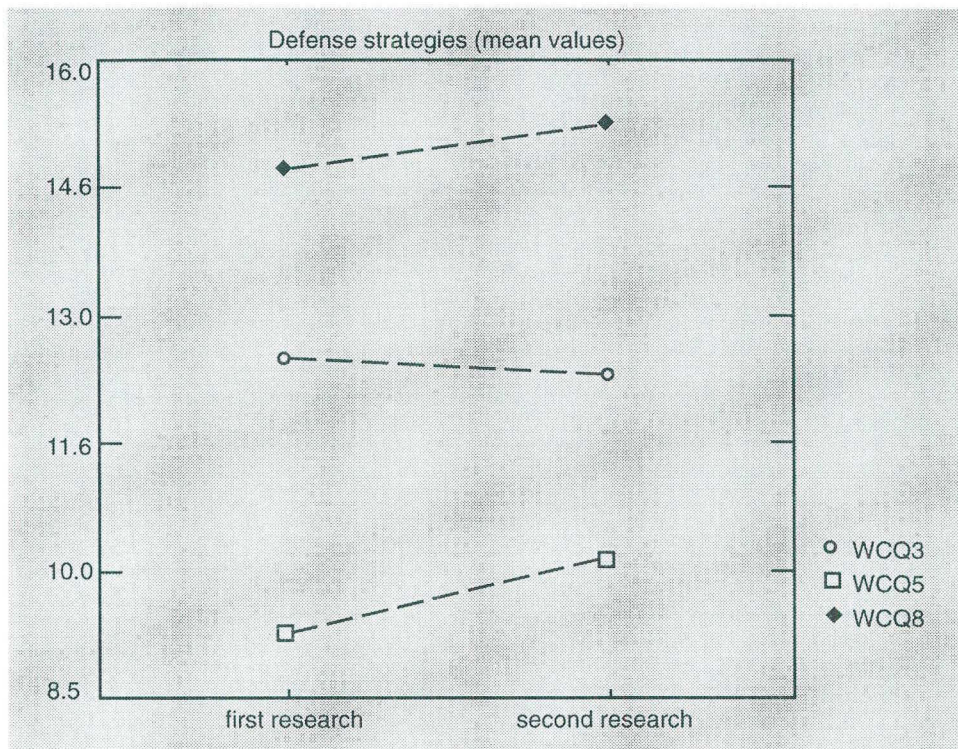
The research was carried out in two steps. The first step was made before parents took part in the quasi-experiment. The second step was taken in the last day of the research. The quasi-experiment was carried out for six months. In that time, parents participated in training for two days once or twice a month. At the very beginning, there were 20 people in the experimental group, but by the end of the training, the number of people decreased to 9. There were two married couples and three mothers of handicapped children. Their children suffered from very serious damage of the central nervous system. These people lived in small towns or in the country. The training was carried out in the Early Intervention Center.

### **THE RESULTS**

In order to check whether the mean values differ in a statistically significant way, for every one the testing of the hypothesis equals two averages ( $H_0$  – hypothesis saying that the averages in the tested groups are equal in corporation with the alternative hypothesis saying that the averages are not equal).

T – student statistics were used in tests. Tests were done for  $\alpha = 0.05$  and  $\alpha < 0.1$ .

Kruskala – Wallis' test was also used.



**Pict. 2. The chart of mean values of parameter of coping (defense strategies) obtain in first and second research.**

Picture 2 presents the values of parameters of WCQ (defense strategies) obtained before and after the parents' therapy. The results point out that the value of the WCQ3 parameter (keeping distance) decreased. The values of the other parameters – WCQ5 and WCQ8 – increased. The results are not statistically significant but very close to them.

**The estimation of social support received by parents of handicapped children.**

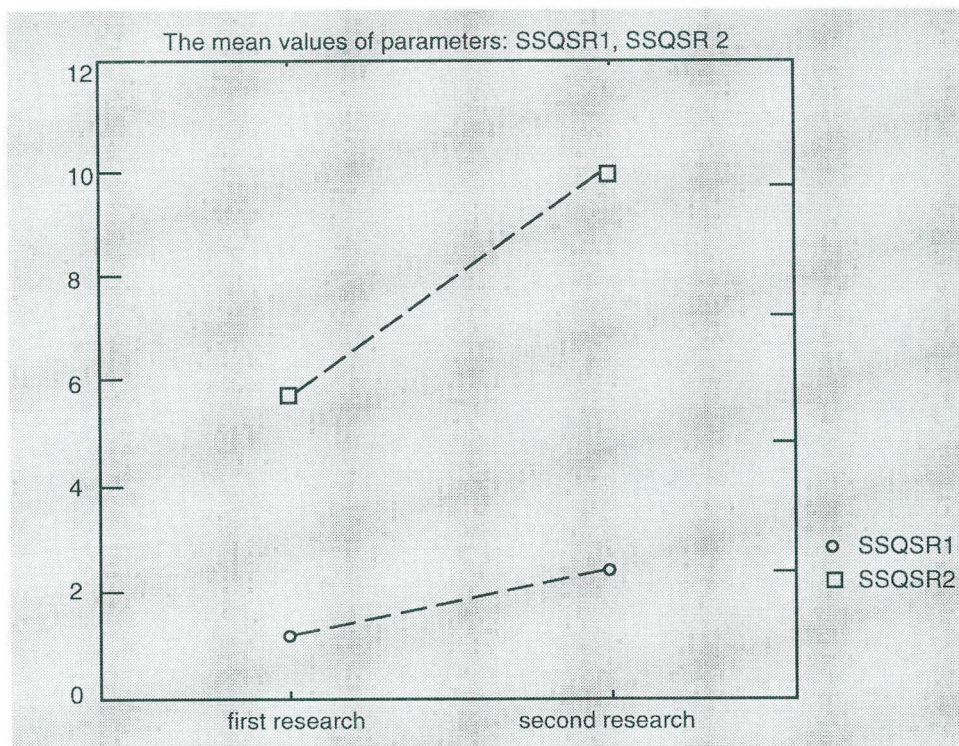
After date analysis, the following results were obtained: in the group of people taking part in the experiment, the mean value for the factor S1 – evaluating the number of people given social support amounts to 1.16 and the max. value is 2.16. The mean value for the S2 factor evaluating the level of satisfaction, is 5.43; and the max value is 10.17. These results were taken before and after educational – supportive training.

The analysis of the mean results for the factor S1 after training is 2.28 and max value is 5.00. The mean result for factor S2 – evaluating the intensity of received satisfaction from the social support amounts to 9.96 and the max value is 21.33. The



- For the parameters S1 apprising the number of people giving support in the first research, the value was 2.167 and in the second one, it was 5.00. For the parameters S2, apprising the intensity of satisfaction from received support – in the first research the value was 10.167 in the second one – 21.333.

- For the parameter S1 apprising the number of people given social support in the first research the value was 1.00 and in the second one it was 4.00. For S2, apprising the intensity of satisfaction from received support – in the first research the value was 4.333, and in the second one it was 16.333.



**Pict. 3. The chart of mean values of social support SSQSR1 (S1) and the level of satisfaction from received support SSQSR2 (S2) for the first and second research.**

The evaluation of level of fear of parents of handicapped children. Analysis of the obtained results.

The analysis of the obtained results shows that the mean value of STA1-1 describing the level of fear as the situation conditional state, in the first research was 45.56, in the second one the mean value was 47.78. The mean value of STAI – 2, apprising the

cation. In the situation when the defense strategies are used, we can tell about flexibility of coping by control of feelings. Many authors (Makowska, Poprawa, 1996) consider this type of coping as the most efficient. Moreover, in the first stage of the process of coping, the full emotional expression serves as “katharsis” and allows to begin cognitive mechanism of coping (Sedek, 1991). Participation in the educational – supportive training led to an increase of the value of strategy, such as stress relief and the increase of strategy – escape-avoidance. It can be explained in this way: that mothers had the possibility to avoid their own problems or were reluctant to face these problems thanks to the opportunity to compare their own problems with those of other mothers. It perhaps led to a daydream of comparative good functioning and development of their children. Answering the question of whether there are any differences in ways of coping before and after the training, it can be said that there are differences; although the differences are not significant. Probably a longer and more frequent training would make the differences more significant.

The second question concerned the changes in received social support. What was surprising was that some people felt no changes before and after the training; however, there are people in whom these changes were significant both in the intensity of satisfaction and increase in the number of people giving the support. These results let me suppose that this type of training can be a good way to receive support, but of course not for everyone participating. Perhaps people who obtained worse results needing long-lasting help of this type of training were disappointed and as a consequence it did not support them.

The third research problem, whether participation in educational –supportive training has an influence on decreasing the level of fear of examined parents can be answered; yes it has. The obtained results show that the level of fear was lowered by most of the parents. This result confirms the important role of therapeutic influence and the change of parents’ attitudes toward the problem of having a handicapped child, because their fears are mended by the constant state of support. Taking into account that the training lasted only 6 months, I can conclude that the results would have been much better if the training had lasted longer.

Summing up, educational – supportive training played an important role in the therapy of parents of handicapped children. It allows parents to relax for a moment in their difficult role of being a parent of a handicapped child. The meeting place of this type is not only a “wall of tears” for many tired of everyday problem parents, but a place where they can receive special professional help as well.

However in Poland, such educational – supportive training is very rare because of financial difficulties and a small group of interested people. The group of people

## **SPECIAL EDUCATION: EMPOWERMENT THROUGH EDUCATION**

**ANUPRIYA CHADHA**

### **INTRODUCTION**

Article 45 of the Constitution of India lays down that free, compulsory and Universal Primary Education should be provided to all children up to 14 years of age. Unfortunately, we have not achieved the goal of Universal Primary Education. The group that has been virtually left out consists of children with special needs. Indeed, when the Constitution was adopted, the founding fathers did not have children with special needs in mind. This is clear from Entry 9 of the state list, which talks of the relief of the disabled and the unemployable. Thus, it would seem that people with disabilities were considered unemployable.

A cursory look at the history of many nations will reveal the contributions made to literary, scientific and cultural development by many people with disabilities. Homer in Greece was immortalized by his writings. So was Surdas in Indian literature. Science has not been out of the reach of people with disabilities. Sounderson, who was totally blind, assisted Sir Issac Newton in the discovery of gravity. Stephen Hawkins, who is severely disabled is a leading theoretical physicist of the world today. Therefore, there is no plausible reason for denying education to children with disabilities. Indeed, such denial implies loss of valuable talent to the community and no nation or community can tread the path of progress without talent.

There has been a proposal to make education a fundamental right. But we do not know whether such an amendment to the Constitution, if ever made, will make specific mention of children with disabilities. Without a specific mention, children with disabilities may be left out.

The only ray of hope is provided by the Persons with Disability (Equality of Opportunity, Protection of Rights and Full Participation), Act 1995. Chapter V of this Act says that appropriate governments shall provide access to free education to every child with disability until he or she attains the age of 18 years. A variety of options including integrated education, special schools and non-formal education have been proposed. But to this day, this Chapter of the Act has remained a declaration of pious intent rather than a basis for a program of action.

#### **Historical perspective:**

Special education in India was imported in the last two decades of the 19<sup>th</sup> century through Christian missionaries. The first School for the Deaf was established in Bombay

conducted by the government of Kerala stated that 10% of the school-going children had learning disabilities. A similar study by Seva in Action, Bangalore puts the number at 6%. The consensus among non-official experts is that 10% of our child population may have special educational needs.

According to UNICEF, India has 300 million children between 0-14 years of age. On this basis, India may have 30 million children with one or more of the disabilities mentioned above. These divergences may be the artifact of different definitions and divergent methodologies. But it is now fairly well accepted that about 10% of our school-going age population, approximately 300 million, have special educational needs.

The government's appreciation of the need to integrate disabled children came in 1974 when the Union Ministry of Welfare launched the centrally sponsored scheme of Integrated Education of Disabled Children (IEDC). Despite concerted efforts in the last quarter of the century, integrated education has had limited coverage. District Primary Education Program has taken the bold initiative of trying to integrate children with disabilities at the primary school level. It would be sometime before the results could be evaluated.

#### **Current educational status:**

No dependable estimates of the number of children who have access to education are reported. However, 2,500 special schools have nearly one lakh students. About 15,000 schools have enrolled nearly 60,000 children under the Integrated Education of the Disabled Children scheme of Ministry of Human Resource Development. A large number of orthopaedically handicapped children attend school without being provided support services. The same applies to children with learning disabilities. Without support services, many of them drop out and may constitute the significant part of school population which drops out after a few years of schooling. Therefore, a national plan should be addressed not just to those who have obvious special educational needs, but also to those whose special needs are not recognized and therefore drop out.

It is clear that not more than 3-4% of children with special educational needs have access to education with or without support services. Most children with special educational needs cannot benefit from education without support services. The very purpose should be to develop support services in a variety of settings in order to ensure implementation of the provision of Persons with Disabilities (Equality of Opportunity, Protection of Rights and Full Participation Act) 1995, to the effect that every child with a disability shall have access to free education and educational equipment between 3-18 years of age.

The current coverage is estimated at about 1%. In other words, in a period of 115

adequate orientation and are provided financial incentives and can start movement in home based special education

Education as part of CBR programs

These are illustrative and not exhaustive options. Under the integrated rural development program and other poverty alleviation programs, special education component could be included.

This plan should, in fact, take the shape of a popular movement rather than a bureaucratically conceived and operated plan. It also needs to be realized that special education without support services, in whatever setting, is without meaning.

### **What do we need to do?**

The need is to develop a firm plan with realistic goals, viable strategies, political will, public support, adequate financial allocations as well as tripartite partnerships between the state, NGOs and parents in bringing disabled children to school and promoting manpower development. The State should exercise adequate regulatory control over the development of special education in order to prevent the emergence of aberrations. Without such a plan, Chapter V of the Persons with Disabilities Act, 1995 would remain a pious wish and a recipe for frustration, rather than empowerment.

In 1947, it was the Federal Government that took the initiative to begin the process of developing special education in gradual stages. This included the establishment of National Institutes as apex research bodies. Likewise, we may urge the central government to make the pioneering endeavor of developing a national plan of special education, giving it the shape of a popular movement that could sweep away all financial, technical and attitudinal problems.

To begin with, the ministries of Human Resource Development and Social Justice could together develop a plan of special education which is child centered and based on the Indian ethos. The views of a wide range of experts believing in different philosophy should be taken and a consensus reached on the most viable plan of action. The assistance of International agencies like the World Bank, UNDP, UNICEF, UNESCO and bilateral aid could be explored to muster adequate resources to launch plan with a powerful thrust.

### **What do we expect by 2020:**

We accept that given the determination and clear-sighted approach, about 25% children with disabilities in India could enter the gateway of knowledge through primary and secondary schools. Knowledge is power and we are trying to empower the marginalised section of the community through knowledge and information to take

SEVENTH BIENNIAL CONFERENCE OF THE  
INTERNATIONAL ASSOCIATION OF SPECIAL EDUCATION  
WARSAW, POLAND

JULY 2001

CALL FOR PRESENTATION AND PAPERS

Robbie Ludy, Program Chairperson, invites all interested persons to submit presentation proposals for the Seventh Biennial Conference of the International Association of Special Education in Warsaw, Poland. Program selection will be guided by the following criteria: (a) quality of the proposal; (b) innovativeness; (c) importance and timeliness of the topic of the field; (d) practical applicability; and (e) how the presentation addresses issues related to exceptionality.

The program theme for the conference will be **Making a World of Difference**. A broad range of topics relevant to special education will be included in the conference program. These areas include, but are not limited to:

- Adaptive/Assistive Technology
- Assessment (traditional & alternate)
- Career Development/Life Skills
- Classroom Strategies/Methods
- Collaboration
- Cultural/Diversity
- Families
- Inclusive Schools
- Personnel Preparation
- Reform and Restructuring
- Research
- Specific Exceptionalities

The conference theme, **Making a World of Difference**, has been designed to promote an exchange of ideas, practices, and future trends for all individuals interested in special education.

To be considered for review, proposals **MUST** include all of the following information:

**Title:** The title should reflect the primary focus of the presentation. The length of the title is limited to 15 words or fewer.

**Completed Proposal Information Form:** All information requested on the form must be provided for consideration. Proposals may be submitted electronically but must include all information on the proposal form.

**A 300-500 word description of the proposal:** This should be a narrative concise description of the proposal. This description will be used for selection and should describe the session's rationale, organization, participant outcomes, timeliness, and applicability in the field. Research proposals should include the statement of the problem, theoretical framework, procedures, major findings and conclusions. Two copies must be provided for the review committee.

**Names and roles of session participants:** The number of participants should be appropriate for the length of the session. Submission of a proposal is a commitment by all individuals participating in the presentation to register for the conference. Presenters are required to preregister to assure publication of information in the conference program and monograph.

Proposals must be received by October 15, 2000 and must relate to the conference theme. Presentations and proposals must be prepared in English and typed or word-processed.

Proposals will be evaluated by conference review teams on clarity and organization, content relevant to educational and cultural practices, systems of service delivery and the future development of these practices at national and international levels. Applicants will be notified in writing of the acceptance of the proposal. All persons accepted to present at the Seventh Biennial International Association of Special Education Conference must submit a paid registration for the conference.

IASE will provide an overhead projector and screen for presenters. It is understood that any additional equipment is the responsibility of the presenter.

For more information regarding the conference or to submit a proposal, contact: Dr. Robbie Ludy, Associate Professor of Special Education, Buena Vista University, Box 2949, Storm Lake, Iowa (USA) 50558.

(O) 712-749-2171 Fax (712) 749-1408 E-mail: ludy@bvuu.edu.

**HUNTER'S SYNDROME**  
**HUNTER'S SYNDROME: DESCRIPTION AND**  
**EDUCATIONAL CONSIDERATIONS**

**TERESA NAGGS**  
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**PORTALES, NEW MEXICO**

**ABSTRACT**

Hunter's Syndrome is a rare, genetic lysosomal storage disorder, resulting from an absence of the enzyme iduronate-2-sulphatase. Boys born with this sexlinked disease are born with little or no clinical manifestations, but generally are diagnosed by the age of three due to developmental delays. This progressive disorder results in early mortality and presents a myriad of considerations for the special educator. Progressive physical and cognitive disabilities in these children offer the special educator a chance to work with a team of professionals to provide these children with an appropriate education and a better quality of life. Behavioral interventions can help children gain more control over their hyperactive and aggressive behavior. As part of the collaborative teaming of professionals, parents are vital to the successful education of these children. Collaborating with parents is essential to a successful program.

**Hunter's Syndrome : A Description and Educational Considerations**

Hunter's Syndrome, type A is a rare disease which leads to multiple impairments and early death (Young and Harper,1983). Although this type of disability is low-incidence, teachers can learn effective ways to educate students with Hunter's in the least restrictive environment ( Lewis and Doorlag,1995). With the passage of special education laws, special educators and general educators will have physically, behaviorally, and cognitively disabled children in their classrooms (Shaughnessy,1996). In addition to educating these children, teachers will be working with members of the collaborating team who are specialized in specific areas. These team members will work along with teachers to educate, and assist these students. Parents are also a part of the collaborative team.

Teachers need to become sympathetic to the needs of the families, so that the families become involved in their children's education (Simpson, 1996). Becoming familiar with all aspects of Hunter's Syndrome, learning methods to assist the education of children with this disease, and collaborating with other professionals and parents will increase the quality of the children's education and life.

**History and Description of Hunter's Syndrome**

Hunter's syndrome is one type of lysosomal storage disorders known as mucopolysaccharidoses (Muenzer, 1986). The mucopolysaccharidoses (MPS) are

with elevated intracranial pressure. Some have had cognitive improvement with relief from a shunt which drains the fluid.

Behavioral problems include degrees of hyperactivity and variable destructive behavior (Young and Harper, 1981). These behaviors change around the age of seven when the children become generally quieter and less active. In the later stages of the disease, affected children become uncommunicative and immobile. At varying stages of the disease, but generally after the age of seven, it is common for children to have seizures.

The musculoskeletal manifestations give Hunter's children their characteristic appearance (Muenzer, 1986). They are generally normal in appearance at birth. Around the age of two or three, changes in the facial appearance become apparent. Facial hair becomes increasingly coarse and thick. Eyebrows become thick and dark. The bridge of the nose becomes depressed and there is a progressive thickening of the nostrils, lips, and tongue (Shapiro, Stome, & Crocker, 1985). The temporomandibular joint or the jaw becomes stiff and painful resulting in poor jaw movement and reduced chewing of food.

As Hunter's syndrome progresses, perhaps because of limited use, muscles become atrophied and tight Achilles' tendons are common (Young & Harper, 1983). Their arms and legs will increasingly retract, limiting their range of motion. They have limited rotation of their heads and wrists.

Respiratory problems are the leading cause of mortality in children with severe Hunter's syndrome (Shapiro, Stome, & Crocker, 1985). These are caused in part due to decreased mobility of the chest wall and deformities in the trachea and bronchial cartilages. Other problems result from upper airway obstruction, and obstructive airway disease. Early on, children have excessive mucous in their upper airway and recurrent rhinitis (nasal infections). A study of 31 cases show frequent upper respiratory infections, including tonsillitis, laryngitis, and otitis media. There are often thickened secretions in the nasal passages and trachea. The tonsils and adenoids are enlarged. Anesthetic procedures become difficult as a result. Sleep apnea (the cessation of breathing for a period of time) occurs in many cases. Recurrent bronchitis and pneumonia are common in the later stages of the disease.

Gastrointestinal manifestations in cases of severe Hunter's syndrome include enlargement of the liver and spleen, chronic diarrhea, and inguinal and umbilical hernias (Young & Harper, 1983). Large livers and spleens are common in affected children resulting in protruding abdomens. Chronic and intermittent diarrhea is a common feature. Many children are treated early in the disease for inguinal and/or umbilical hernias. Some children with severe Hunter's syndrome have degrees of visual and/or



### **Musculoskeletal**

Detection of Hunter's syndrome occurs in the first three years of life because children miss developmental milestones. Young and Harper (1983) report the following developmental delays in their study of 52 children. For 26 cases, the average age for sitting unsupported was 8.1 months. In 42 cases studied, the average age for walking was 15.7 months. Joints become progressively stiff. The fingers and hands become "clawed" or contracted. This makes fine motor skills increasingly difficult. Occupational therapists can help children gain skills, and with vigorous therapy, limit the contractures to a degree. Using functional skills such as rolling out play-dough, or pushing doors open using the palms of their hands are examples of functional therapy (Shea & Bauer, 1994). Besides fine motor disabilities, children with severe Hunter's have gross motor impairment. The legs and arms become restricted in their movement. Physical therapists can provide activities that will stretch the muscles. Activities for stretching these muscles can be naturally occurring like jumping on a trampoline, and riding tricycles or other car type vehicles where their legs are fully extended at some point. This will delay the progression of muscle atrophy and the contraction of large muscles. Passive stretching and bending of the joints can cause damage and pain (MPS Society). Boys with Hunter's are generally very active and love to play.

### **Respiratory**

Recurrent chest infections are common in children with severe Hunter's syndrome (Shapiro, Stome, & Crocker, 1985). As with the other tissues, mucopolysaccharides build up in the lungs, cartilage, and other areas of the lungs. The breastbone is not as flexible as it should be and the shape of the chest is abnormal. As a result of this, large internal organs and the lungs have an increased amount of secretions which are hard to clear. Clearing the system of secretions becomes more difficult as the children age. They often have productive coughs. This becomes worse when they get bacterial infections or allergies. Parents, school nurses, and/or the family physician can help the collaborating team select the best posturing and intervention to help make them more comfortable. A physiotherapist can instruct teachers how to administer postural chest drainage.

As a result of respiratory involvement and trachea deformity, sleep apnea is common (Shapiro, et al, 1985). Another possibility for sleep apnea was suggested in a case study (Kurihara, Kumagai, Goto, Imai & Yagishita, 1992). Kurihara et al. described a boy who had frequent sleep apnea. Sleep studies conducted showed an average of 13.3 apnic episodes per hour for a total of 143 episodes in one night. Breathing stopped for a total of 37.4 minutes during the night. Autopsies showed storage material in the

## **Speech**

Young and Harper's (1983) study revealed data on speech development for 36 individuals with Hunter's syndrome. Of the 36, five never spoke meaningful words. The average age for speaking meaningful words for the other 31 individuals was 17 months. Of these 31 individuals, only five had spoken over two or three word sentences. They spoke in repetitive sentences, and exhibited "echolalia or mindless repetition of nursery rhymes" ( p.484). There are some similarities in the speech patterns of children with Hunter's syndrome and autism.

The Indiana Resource Center for Autism lists perseveration and rambling as characteristics of children with autism (1979). Speech and language pathologists can work with individuals to increase their ability to articulate and make their needs known (Shea & Bauer, 1994). Using methods to develop their language concept development will help increase their receptive communication (Thomas, 1986). If they are not able to articulate, other forms of communication such as gestural or aided systems can be considered.

## **Gastrointestinal**

Many children with severe Hunter's syndrome have recurring bouts of diarrhea (Young and Harper, 1983). In their study of Hunter's children, Young and Harper noted 22 out of 36 cases of diarrhea. Possibly related were the details of toilet training for 35 patients. Nineteen never gain control of bowel function and of the remaining sixteen, five never became dry at night. If control is gained, children become incontinent as the disease progresses. Inguinal and umbilical hernias are common. The collaborative team can determine learning priorities for children and decide if toilet training is an appropriate educational goal.

## **Neurological**

One of the defining characteristics of severe Hunter's syndrome is the progressive neurological involvement (Young and Harper, 1983, Muenzer, 1986, Kurihara et al., 1992) Children are slow in reaching developmental milestones and cognitive abilities in general. At some point, they reach a cognitive peak and then begin to lose abilities. Young and Harper (1983) reported developmental regression beginning at age 6 1/2 on the average. The first sign of regression was apathy. They became progressively indifferent to their environment. They were less active, becoming nonambulatory at an average of 11.9 years of age. Speech was lost at an average age of 10.9 years. At an average age of 12.4, patients "had eventually lost all skills and became totally bedridden and helpless." In cases of progressive terminal disease, teachers and collaborative teams can teach as many functional academics, daily living, and social skills as they can before children begin regressing.

appropriate. Anti-social and aggressive behavior needs to be eliminated to increase social interaction. Studies show that positive social relations in young children influence other areas of learning including : intellectual, interpersonal, communicative and emotional development (Bates, 1975, Hartup, 1978, Parker & Asher, 1987, Rubin, 1980, cited in Salisbury, Gallucci, Palombaro, & Peck, 1985). Salisbury et al. (1995) describe five strategies that promote social relations among students who have disabilities and their typical peers. The five strategies are: active facilitation of social interaction, letting children solve problems alone or with little assistance, exercises in empathy, modeling acceptance, and organizing the classroom structure to facilitate group activities.

Strain and Kohler (1995) conducted a study of children with antisocial behaviors. Implementation of social skills training increased the target children's social interaction with typical peers significantly. Teachers of children with severe Hunter's can explore some of these strategies mentioned and incorporate them into their curriculum.

### **General Suggestions**

Children with severe Hunter's syndrome present the educator and collaborative team with many physical challenges. Everyone who is to be included in the children's education should be aware of the nature of the physical aspects of diseases like this and be prepared for any eventuality (Thomas, 1996). They must become familiar with daily medical procedures. Preventative care such as cutting up food into small bites, positioning children to facilitate breaking and prevent choking, encouraging range-of-motion exercises to slow muscle contractures and decrease muscle atrophy are all aspects of education which should be considered when dealing with students like these. Teachers need to have good collaborative skills with other professionals like occupational therapists, speech and language pathologists, physical therapists, the school nurse, respiratory therapists, and others to provide an appropriate education and interaction with typical peers in the least restrictive environment (Lewis and Doorlag, 1995). Some of the most important members of the collaborative team for students with severe Hunter's are the parents.

### **Parent Collaboration**

Parents are an integral part of the collaborating team for students with severe Hunter's Syndrome (Simpson,1996). They are especially important in constructing the individualized education plan. They are valuable in the assessment of all areas of the child's education. They can work with the team in helping their children meet educational goals. Many times they must advocate for the needs of their children. They know their child better than anyone else and can provide helpful insight on what works best of their child. Simpson suggests that in order for parents to function to the

of the way these programs are arranged.

The way various family-oriented human service programs can be arranged was the focus of a study by Trivette, Dunst, Boyd and Hamby (1995). Trivette et al. identified four paradigms for differentiating between these programs. In professionally-centered models, professionals are considered to be the experts who determine the needs of the child and the family. Family-allied models utilize the family in the interventions that the professionals deem appropriate; family-focused models consider families to be consumers of services, and thus assist families in making choices among options deemed appropriate by professionals; family centered models view professionals as instruments for families. Family-centered models with frequent contact from help givers who used empowering help-giving practice resulted in greater indication of personal control by family members. Agosta and Melda (1995) also recommended familycentered models for services. They suggest that parents need to feel empowered and in control of decisions that affect them. Family centered human service programs appear to empower families. Parents can learn to advocate for family needs and teachers are mandated to inform them of their legal rights in the education of their children (Simpson, 1996).

Teachers of children with disabilities like severe Hunter's syndrome need to be aware of legislation that pertains to the rights of families regarding the education of their disabled child (Simpson, 1996). The Individual with Disabilities Education Act (PL 101-476) provides families with a number of rights. This document needs to be available for reference by teachers. It includes the following provisions for families :

- (a) identification and provision of a free and appropriate education for all children.
- (b) assessment that is nondiscriminatory and individualized.
- (c) protection from inaccurate placement or denial of equal education and protection through due process.
- (d) placement of students in the least restrictive environment.
- (e) Individualized Education Plans (IEPS) which ensure individualized appropriate education.
- (f) opportunity for parents to participate in their child's education.

Teachers are required under the IDEA to inform parents in their native language or a language they understand of their rights of due process.

Due process under the IDEA includes the right of parents to have access to their child's records (Simpson, 1996). Parents have the right to have their children evalu-

Parents of children with Hunter's Syndrome often write to a publication about various topics of concern. *Courage Magazine* is a publication about various MBPS diseases. Parents frequently refer to their affected children as being lovable, popular, coordinated in some sports, and good natured (1996,1997). Despite the failure of authors and researchers to address the strengths of these children, teachers and collaborating team members can and should plan for their education on an individual basis. The IDEA provides a structure for the development of an educational plan that is based not only on the student's weaknesses but also on his/her strengths. Parents become especially vital in the development of the educational plan and can provide this type of information on an individual basis. Parents can become more involved in their children's education when teachers assist them in validating family concerns, offering resources for the family, informing them of their legal rights, and suggesting ways to become advocates for their children. Teachers need to be trained in collaboration techniques, become familiar with local resources for families, have access to and become familiar with the rights of due process as outlined in the IDEA, and facilitate parents in becoming advocates for themselves and their children.

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**STRATEGIES FOR THE CONTENT AREAS**  
**STRATEGIC INSTRUCTION IN THE**  
**CONTENT AREAS USING MNEMONICS**

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**INTRODUCTION**

How we teach and what we teach has long been a point of discussion of educators and parents alike. In today's globally transient society, teachers are charged with the task of educating diverse groups of students. Parents expect their children will or should learn from the instruction provided for them in educational environments.

As we move into an increasingly more complex and technologically oriented society that brings the people of the world closer together, closing the gap between cultures and physical miles, the dilemma facing educators today is not so much the content of WHAT to teach but, rather HOW to teach. This is so that all students learn and manage the vast amounts of knowledge they will be expected to assimilate in their lifetime. To illustrate just how much information is out there to be mastered, Toffler (1997) notes that by the year 2002 knowledge will double every 73 days. A teacher can not possibly cover all the content that is required to keep up with such dramatic information explosions. Rather, the teacher must provide the student with tools they can use to facilitate the 'acquisition, manipulation, integration, storage, and retrieval of information across situations and settings' (Alley and Deshler, 1979). Students must be able to dissect the vast amounts of information given them and be able to discern that which is important and why.

The goal of educators is to create a learning environment that produces independent and lifelong learners capable of sifting through the information that is predicted to change every 73 days. One way to accomplish this goal is to present information through strategic instruction.

**What is Strategic Instruction?**

Strategic Instruction involves the utilization of effective teaching practices. Two terms are most widely associated with strategic instruction: Cognitive Learning Strategies and Learning Strategies. Both are similar and often used interchangeably.

taught.

Mnemonic strategies have long been recognized in educational arenas in some form for decades. For example, Robinson in 1961 developed the study skills mnemonic SQ3R which was, and still is widely used for organizing, reading, and reviewing written content in science and social studies in both general and special education. The use of mnemonic strategies gained widespread recognition in special education in the mid 1980s with the work of Deshler and his colleagues at the University of Kansas's Center for Research and Learning.

### **What Are Mnemonic Strategies?**

Mnemonic Strategies are enhancements that help students remember content. They are verbal or pictorial cues that can be used to strengthen or increase memory and help recall unfamiliar information (Mercer and Mercer, 1998). This is done by creating a mnemonic which cues the student to 'chunks' of information or steps necessary for success with a given task. In Robinson's SQ3R strategy, the chunks include survey (S), generate questions (Q), read for answers, recite facts needed, and review important information (3R's).

Another mnemonic example is RAP (Ellis & Lenz, 1987) which allows students to identify and store information contained in a paragraph; thus, facilitating comprehension. RAP cues the student to:

**R:** Read a paragraph

**A:** Ask yourself, what is the main idea and two details?

**P:** Put the main ideas and details into your own words

A teacher wishing to teach RAP to her students would first, as with any lesson, introduce the topic or concept to be taught. In this case the teacher tells the students they are going to learn a strategy that will help them understand what they have read by finding the main ideas and details contained in paragraphs. The teacher then directs the students attention to each letter in RAP explaining its purpose. Modeling of the desired behavior follows with the teacher giving the students a paragraph and asking them to do the first step in RAP, read the paragraph. After the students have read the paragraph, she cues them to the A in RAP which asks what is the main idea and what are two details. Finally, the teacher directs the students to engage in the P, put it in your own words or paraphrase. She then provides an opportunity for guided practice by giving the students a second paragraph to try on their own or in dyads, or triads.

We can see from the above illustration that implementation of mnemonic instruction is relatively simple. RAP is an example of a First Letter Mnemonic and is the



- P Predict ideas in the text based on background information
- O Organize the predicted ideas into a map or tree
- S Search text by reading (SQ3R)
- S Summarize the main ideas and record on map or tree
- E Evaluate comprehension by:
  - comparing the information on the map
  - clarifying by asking questions
  - predicting what information will be in the next portion of the text

Ellis and Lenz (1987) developed the simple **CANDO** strategy to help students in second grade or higher with content information.

- C Create a list of items to be learned
- A Ask yourself whether your list is complete
- N Note the Main Ideas and the Details on a map or tree diagram
- D Describe each of the components on your map or tree and how it relates to others
- O Overlearn Main Points and build with Details

Another strategy developed by Ellis and Lenz (1987) is **FIST**. **FIST** is a self-questioning strategy to enhance reading comprehension of students in any grade.

- F First sentence in the paragraph is read
- I Indicate or formulate a question from the information in the first sentence
- S Search for the answer
- T Tie the answer to the question by putting into your own words (paraphrasing)

#### **Mnemonics for WRITTEN EXPRESSION and HANDWRITING**

**COPS** (Schumaker, Nolan, & Deshler 1985) is one of the earlier mnemonics developed by the researchers at the University of Kansas Research and Learning Center. **COPS** is widely used in general and special education classes alike and cues the students to check their written work.

- R Read the problem—correctly!
- I Identify the RELEVANT information
- D Determine the OPERATIONS and the UNIT for expressing the answer
- E Enter the correct numbers, calculate and check your answer

Another mnemonic for story problems said to have been developed by students in a middle school is Don't be a word problem **WIMP!** (Sealander 1992). WIMP helps students identify the important information from the extraneous information.

- W What information do you have
- I what is the IMPORTANT Information?
- M Make an equation using the important information
- P Put a label on the answer (e.g. feet, inches, miles, minutes, hours, etc.)

To help students learning place value, the **FIND** mnemonic (Mercer and Mercer, 1998) provides organization.

- F Find the columns
- I Insert the T bar s (  $\begin{array}{c} \underline{4 \quad | \quad 7 \quad | \quad 5} \\ | \quad \quad | \end{array}$  )
- N Name the columns
- D Determine the number of tens, hundreds, thousands and ones

### CONCLUSION

The strategies presented here are simple, but powerful tools to help students acquire and use the vast array of information they will be expected to learn. Strategic instruction has many advantages. It promotes success which, in turn, serves to motivate the learner. It provides the **HOW** to teach for the educator and the **HOW** to learn for the student traditionally, the focus for the student has been on **WHAT** to learn.

Strategic instruction utilizes effective teaching principles and has as a focus on student strength rather than deficit. It is an active learning medium rather than a passive medium. Strategies promote awareness of performance, alerts the student to the need to alter behavior, and provides the steps to make the requisite alternations.

If, as educators say, the goal of education is facilitate independent and life long learners, teaching learning strategies is an effective approach.

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