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ABSTRACT

Described in 13 case studies of deaf blind (as a result of rubella) children are medical, economical, emotional, and professional factors that add to stresses of parents. Medical factors are examined in relation to frequent hospitalization of the rubella children before 18 months of age. One of the case studies shows how young adult parents were so traumatized by their infant's hospitalizations (69 days) that they were unable to use medical or educational assistance for 7 years. Economic factors are said to involve expenses for many specialists: cited is the case of a 4-year old child whose parents worked to meet surgery expenses and were denied public assistance because their combined income was above the poverty line. Emotional factors are described to include initial shock of parents on learning their child is defective and subsequent behavior, such as withdrawal and resentment, which complicates the child's need for a close relationship. A further stress is attributed to the lack of affectionate behavior, typical of deaf blind children. Illustrative of additional stresses on parents is the screaming, flooping, or seizure-like behavior of a 2-year-old who later, at 4 years of age, showed some affection for her grandfather but none for her mother. Professional factors are described in a case study showing the dilemma of parents who attempt to follow conflicting professional advice. Professionals are advised to be sensitive to perceptual differences and to work out a plan of action toward mutual goals to help families with handicapped children. (MC)

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THE CAUSES FOR STRESSES IN FAMILIES WITH DEAF-BLIND CHILDREN

The birth of a perfect child brings joy and excitement to most any parent. But the birth of a handicapped child only gives the parents grief and distress. The continuing caring and raising of a handicapped child brings on even more heartaches and sorrow and many, many stressful experiences are being faced by their families. The following are some of the reality factors seen as the causes for these stresses. They are divided into four categories: Medical, Economical, Emotional and Professional, and case materials are used to illustrate how different factors cause and produce stresses to these families with deaf-blind children.

I. MEDICAL FACTORS

Most developmental research has indicated a child's first five years as being the most important years for his growth and development. Recent studies and clinical observations and experiences suggest the first 18 months as being even more crucial and important for a child's development, both physical and emotional. Looking at the available medical data on the deaf-blind children that the Child Study Center of Oklahoma University Health Science Center is familiar with, one can easily see the early environmental deprivation for these children due to the many hospitalizations most require during their first 18 months of life.

The attached table is a study showing hospitalizations of 13 rubella children, age range from 2 to 13. We see that number

2 child spent a total of 69 days in the hospital before she was 1½ years old. The shortest stay was by child number 6. He only spent 4 days in the hospital before he was 1½ years old. The average hospital stay for the 12 children with known duration of hospitalizations was 26 days, which is rather high. Most of these hospitalizations were for cataract and cardiac surgeries and prolonged diagnostic evaluations. Some of these children had such low birth weights that they required long hospitalization during their neonatal periods. Childhood diseases and infectious diseases caused many of them to be hospitalized because of their low physical resistance.

Some explanations follow about the selection of these particular children. While there are over 40 deaf-blind children known to the Child Study Center, 15 of them are known or diagnosed as "rubella children" and one is post encephalitic. Others are mostly of unknown etiology. I selected the rubella children for two reasons. First of all, since this is a congenital disease, impairments of the children occurred prior to onset of birth, producing stressful experiences to the family from the beginning. Secondly, the rubella children do represent the most typical of both deaf and blind handicapped children. Please note on the graph that 10 out of 13 children are both deaf and blind. I might need to insert here that while all of them are legally deaf and blind many of them have partial sight and some of them have residual hearing left. Number 9 child is the only child that has one major sensory loss, the deafness,

CASE RECORDS OF THIRTEEN RUBELLA CHILDREN

Child Study Center
Oklahoma University Health and Science Center

o.	Age	Sex	Impairments	Days in Hospital (1-18 Months)	Total Days
1	13	M	Deaf/Blind	(7 @ 4mos.) (7 @ 17mos.)	14
2	7	F	Deaf/Blind	(17 @ birth) (52 @ 1mos.)	69
3	4	M	Deaf/Blind	(8 @ birth) (6 @ 15mos.)	14
4	6	F	Deaf/Blind	(4 operations about 4-5 days each)	18
5	7	M	Deaf/Blind	(21 @ birth) (14 @ 2 mos.) (5 @ 12mos.) (8 @ 18mos.)	48
6	4	F	Blind/Lang. Delay	(4 @ 18mos.)	4
7	5	M	Deaf/Blind	(3 @ 5mos.) (6 @ 7mos.) (7 @ 14mos.) (7 @ 15mos.)	23
8	5	F	Deaf/Blind	(4 @ birth) (12 @ 5½mos.) (7 @ 18mos.)	61
9	4	F	Deaf	(12 @ birth) (8 @ 1mo.) (12 @ 12mos.)	32
10	2	M	Deaf/Blind	(5 @ 6mos.) (5 @ 10 mos.) (2 @ 13 mos.)	12
11	5	M	Deaf/Blind	(12 @ birth)	12
12	6	M	Blind/Lang. Delay	(7 @ 3wks.) (7 @ 6mos.) (7 @ 12mos.) (9 @ 18mos.)	30
13	4	M	Deaf/Blind	(Incubator after birth) (Duration unknown)	?

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and her vision is slightly abnormal with esotropia. The arbitrary number of 13 is not all that arbitrary because out of 15 rubella children 13 are from Oklahoma, one from Hawaii and one from Texas. The two out-of-state children's medical information was not readily available to us, thus, they were forced to be eliminated from this study.

Going back to the children's long hospitalizations, look again at child number 2 with 69 days of hospital stay. This is a child born to a very young couple: her father was 20 and her mother was 18 at the time. She was the first and only child in the family. The family is on Aid to Families with Dependent Children and both the parents came from low income backgrounds. The child stayed at the hospital for 17 days at birth because of low birth weight. Then she had to be re-admitted when she was 4 weeks old due to her failure to thrive. She was diagnosed as having bilateral cataracts and pulmonary disorders and doctors recommended surgeries. However, since the child had such poor physical history and the long hospitalizations were so traumatic to the parents, at age 7 she had not had any of her corrective surgery. This child is functioning on a very low level and the parents have not been able to use either the medical or the educational assistance offered to her. They admit that they are too scared to touch the child since she might literally "drop dead" any day. Another case, child number 8, was also born to a very young couple and this is their first and only child. She stayed in the hospital for 42 days after birth because of low birth weight along with difficulty in feeding. At 5½ months she had a heart catherization and the ligation of paten ductus arteriosis was done at that time. She had her first cataract operation at 18 months old. When she came to us at the age of 3 for an evaluation she was functioning on an overall 1½ year level. There seemed to be much more potential in the child. However, when we visited with the parents, it was indicated by them that for the child's first 2 years they did not even know whether she was going to live or die. Consequently, they could not bring themselves to make any demands on the child even though that might have hindered the child's growth. Her parents must have encountered many stressful and frightening experiences during that child's early life when it was being threatened with death constantly. Their fear of making demands to the child is clearly understandable.

Of course, the hospitalizations described here are only major critical events in these children's lives. Many other emergency calls and doctor's office calls for these children are almost too numerate to count. Not to have gone through the same experience one probably cannot fully understand and empathize with the parents regarding the extraordinary emotional demand and strain made upon them due to their handicapped children's poor physical condition.

II. ECONOMIC FACTORS

Closely connected with the medical factors, the economic or financial burdens are added stresses to these families. The numerous hospitalizations and surgeries strain the pocket books of most of these families with deaf-blind children. Then the many office calls and visits to the specialists such as the ophthalmologist, audiologist and neurologist add up the cost quickly. Later when corrective lenses and hearing aids are prescribed the added burden becomes a real struggle for many families. Yet by many states' welfare regulations the middle class are not eligible for any assistance with their medical expenses.

One 4 year old deaf-blind rubella child has been wearing glasses since he was 2½ years old. Because of the different corrections needed for his use (his glasses are bifocals with four other kinds of corrections), the regular glasses would weigh so heavily that they would literally "weigh him down." (Because he is a rubella baby, very small and thin in size, it wouldn't take much weight to weigh him down.) The plastic glasses for this boy cost $120.00. Yet because it is plastic and because of this child's young age and his requiring to see objects from a very close range (he is legally blind) the average time of wearing of his glasses has been about 6 months each pair. The young parents of this boy have been trained through vocational rehabilitation and are both working in relatively low-paying jobs. Since there is a baby in the family, the wife can only work part-time and their combined income is about $600 per month. The glasses, even as expensive as they are, are relatively small expenses in comparison with the several cataract surgeries he had to have. Yet the welfare department had repeatedly denied them assistance because their income is above the poverty line. You can imagine the stresses this particular family has in trying to meet their financial obligations in regard to meeting their handicapped child's needs.

Then there is the ever increasing cost for educational and remedial programs such as speech and language therapy and physical and occupational therapy. While cost of public and other clinics are nominal, private clinics do have higher fees and parents with deaf-blind children are only too familiar with running here and there to different clinics and agencies in order for them to provide the most available remedial therapy for their children.

Some mothers are compelled to stay home with their handicapped children even though they have been professionals and enjoyed working outside of the home. Many of them have expressed their regret about their not being able to work and the loss of additional income. Those that have to work because of financial necessities are so guilt ridden that they are in a constant state of struggling between their guilt and bank balance.

III. EMOTIONAL FACTORS

The presence of a handicapped child in any family tends to result in intense emotional reactions by the parents. The initial emotional reactions of the parents to the handicapped child usually are so full of shock and disbelief that many of them find it hard to describe as to their exact reactions toward the birth of a handicapped child. The birth of a child is a momentous occasion and long before birth the parents idealize the child, a normal and perfect child. While many normal children do not live up to the often realistic expectations of their parents who therefore must gradually give their cherished plans up, parents who receive a diagnosis of handicapped child have their plans for the child brought to an abrupt end and all their dreams and hopes are gone like that. At the time of discovery when the parents realize or are told by a specialist that the child is handicapped, they experience this natural emotional shock. Later refusal, withdrawal, guilt, bitterness, resentment, and rejection are usual manifested reactions. And all parents experience these whether they realize or acknowledge it. Yet as with any person the handicapped child needs close and satisfying relationships with meaningful persons surrounding him. These relationships must be satisfying and involve the least amount of stress if he is to achieve his maximum potentiality. Dr. Harold D. Love in his book on <u>Parental Attitudes Toward Exceptional Children</u> stated that the welfare of the child depends in a large measure on the well-being of the parents and the emotional reactions of the parents lead to the child's own adjustment or maladjustment. Thus, a paradox almost exists in the situation of families with deaf-blind children. While one of the typical characteristics of deaf-blind children are their touch-me-not or "affectionlessness" behavior, these infants rely exclusively on their mothers for their survival and development versus the normal child who through visual and hearing input (support) receive supplementary feedback from the environment. Since mother/child relationship is such a close tied relationship as well as a reciprocal relationship, one can understand how frustrated and despairing the mother must feel because of the usual negative feedback she gets from her deaf-blind child. A 4 year old totally blind girl with no language and questionable hearing is reported to be a touch-me-not baby from birth. She does not have any self-help skills (eating, dressing and toilet training). She started to have very bad temper tantrums when she was 2 years of age, screaming, rolling, flopping and jumping up and down, and almost seizure like behavior with loss of control of herself periodically. She has been improving some this last 6 months, according to the parents and "coming out of herself a little bit." So today she will show some affection toward her maternal grandfather but he is the only one that receives any of her affection. This mother is 24 years old. This is her first and only child and she stated specifically that she will not have anymore children. You can understand what the past 4 years were like for this young woman to have lived with a child such as this. No response or rather no positive response from their handicapped children and yet being required to give so much more of their time, energy and themselves finally just drove most of these parents into a very vulnerable, emotional state of being, even though they might have started out with rather healthy and stable emotional strength. It is true that parents react to the child's handicap on the basis of their total personalities and patterns of reacting to any critical life events as Dr. Love indicated in his book. Their coping mechanism toward life in general prior to the arriving of the handicapped child, usually determines how they react and cope with the handicapped child. However, our observation at the Child Study Center and working with parents of deaf-blind children show that even the most stable and mature families can gradually be worn out and slide back in their coping strength after years and years of living with the daily emotional stresses of caring for these handicapped children.

In thinking of emotional stress for the family with handicapped children, the comment from a mother of a 17 year old deaf-blind boy with post encephalitis is most descriptive in what it is really like to be the parents of a deaf-blind child. When asked what was the most difficult or stressful experience of caring for this boy in all these many years, the mother responded by saying that "it was not to have a moment by ourselves (meaning for her husband and her). We constantly have to worry where Robert is. Even when he was attending a meeting somewhere, we would still be worried when the time comes and he is not home yet. We wondered if he was being left somewhere and that his ride had forgotten about him." She added, "With a normal child you don't worry as much but with a deaf-blind child you worry all of the time."

IV. PROFESSIONAL FACTORS

Adding this last factor for causing stress to families with deaf-blind children might cause some of you to wonder about the validity of my doing so. I would have wondered about the same thing prior to my working closely with these families. However, after working with these families I'm most convinced that while I might be able to give you some cases in any one of the previous categories as causes for producing stress, I can give you all of my cases and tell you how each of the families have been imposed upon by professional demands that actually have produced more stress to them. Let me illustrate with case number 4, age 6, a legally deaf-blind girl. Her last audiological evaluation on May 27, 1972 indicated that she exhibited profound sensory neurological loss of hearing bilaterally. At the age of 6 she has "b", "p" and "m" sounds and mostly some guttural sounds. She attended an oral school for the Deaf for 2½ years and by the end of this 2½ years the parents were highly frustrated because of her slow development and little growth in all areas except social adaptive behavior. She had no language or communication skills at the age of 6 yet the parents were looking for another oral deaf school for the child, hoping she will develop speech soon. After evaluation, the Child Study Center offered the child a supplementary program in order for her to finish her school year at the other school and yet receive some individual tutorial program here at the Child Study Center. Sign language was excluded for this tutorial program because it is accepted by neither the parents nor the other school. In spite of those limitations this girl had been functioning on a 3 to 4 year old l[illegible] except in language. She showed much potential and seemed to be benefited greatly from the individually prescribed educational program here at our center. However, it was too disheartening to see a tall, 6 year old girl hopping and jumping up and down because she failed to make the teacher understand that she needed to go to the bathroom. Along with other obvious reasons for the child to have some kind of communication skill, the staff decided to insist upon a total communication approach with this child for next school year and offered a whole day program for the child for the school year of 1972-73, if parents would allow us to use the total communication approach with this girl. (The mother had indicated from the beginning that she would not enroll the child at the other school for the school year 1972.) Counseling and scientific data on total communication along with pamphlets and bibliographies were given to the parents in order for them to be familiar with the facts and information regarding total communication. They were given from May to September to reconsider their feelings about sign language and to evaluate for themselves the urgent need of their child to acquire communication skills. In the meantime they sent the child to another private oral school summer language camp for 8 weeks, spending considerable amounts on tuition. They were turned down with their application for their child to enter the school for the fall. At the end of

August when the parents were contacted by me to ask of their decision as to where they planned to send their girl to school they were asking instead for a referral to an oral deaf-blind school for the child. That aroused considerable amounts of panic and frustration on our part, needless to say. Finally, at the beginning of September, the parents failed to find such a school and agreed to send the girl to our school and allow us to use total communication approach. In fact, the mother now is taking sign language with an instructor herself and she is one of our most enthused sign language parents. She frankly told us that "it was most difficult for us to accept sign language because after all we had 2½ years of constant drilling about how bad sign language is for deaf children." Setting aside the different philosophies professional people have in regard to total communication one must ask if professional people do take into consideration the needs of the individual child and how they should be responsible for the child's needs. Regardless of our own personal bias and feelings, imposing our biases and prejudices upon the parents only produce the uncalled for stresses to these families who really already have too much to cope with anyway.

Each parent of a handicapped child needs a professionally trained specialist at many points along the way. It is likely that each parent could put together a sizeable list of professionals with whom they have come in contact in some manner.

The pediatrician, neurologist, psychiatrist, ophthalmologist, audiologist, psychologist, physical therapist, speech therapist, social workers and educationlists probably are all included on the list. Each professional is brought up in a prescribed course in specialized training in his respected field. Each of these professionals in turn will exert certain amounts of influence on the parent of the handicapped child. Many times parents are distressed upon the lack of agreement upon professionals. A wide variety of opinions are expressed to the parents, for example, total communication vs. oral method only. While professionals still debate with each other in their laboratories on theories the parents are suffering with their handicapped children.

Another area of stress imposed on the parents is the different perspectives parents and professionals have in regard to the handicapped child. Dr. Ray Barsch in his study of child rearing practices of the parent of the handicapped child put it this way. "The professional wears one kind of lens ground in the laboratory of his collegian orientation and experiential background which he can call upon in asking his observation. The parent of the handicapped child wears another kind of lens ground in the laboratory of prosaic daily living, hopes, ambitions, personal complexity and sophistication. The lenses are not identical. They have been grounded for different purposes and refract illuminating information accordingly. These 2 different kinds of perceptual lenses cause each respective observer to view the child differently. In other words, the parent cannot be expected to perceive the child in the same manner as the professional does. These 2 inevitably different perceptions have often been the cause of distrust and a loss of respect. It is really a problem of perceptual incompatibility."

I would like to add that it is more important for the professional to recognize and acknowledge perceptual differences and in turn to interpret these to the parents. If we are to serve and offer help to these families with handicapped children, we need to work out a plan of action toward some mutual goals. In closing, I would like to quote a paragraph written by Ruth Page on "Co-Parenting." The article was in August, 1972 edition of Newsletter of Special Education Information Center - "Nobility is not what parents of handicapped children seek. They seek proper awareness of all people - including professionals, of their capacity to be parents of their children even under highly unusual circumstances, and they ask that those professionals seeking to help handicapped children take a closer look at how these parents, with less training and more unfavorable hours, manage to live their own life and enrich the lives of all their children."

Looking at these families under the different stresses that were discussed here, I often wonder if, given a similar circumstance and stressful situation, I would have done as well as some of these parents have done!

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