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ABSTRACT

The report describes three preschool Swedish children with osteogenesis imperfecta (brittle bones) and the psychosocial support families require from society. Introductory sections explain the condition, review international research on brittle bones, consider the life situation of children with brittle bones, and examine societal support for children with mobility impairments including financial help and habilitation. Much of the paper presents findings from interviews with the three families covering such areas as community support, medical support, psychosocial support, the child's awareness of the handicap, and daily activities. Includes 20 references. (DB)

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THREE PRESCHOOL CHILDREN WITH OSTEOGENESIS IMPERFECTA - INTERVIEWS WITH PARENTS

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UNIVERSITY COLLEGE OF JÖNKÖPING
HANDICAP RESEARCH GROUP

ABSTRACT

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Report No 5, 1990 **ISSN: 1100-9047**

The aim of the study has been to describe three preschool children with osteogenesis imperfecta (OI) or brittle bones and the psychosocial support families of those children can obtain from society. The study is part of a larger research project where all families to children with OI known by RBU (the National Association for Disabled Children and Young People) in Sweden participated.

The study is based on reviews of literature and interviews with parents.

The study shows that the families are in great need of support. They often feel fearful that their children will get fractures when they are together and play with other children. Therefore the families tend to withdraw from other people. Knowledge of OI in Sweden is poor partly due to the fact that only about five children every year are born with this disease. In many cases the children are diagnosed rather late and in the meantime the parents are sometimes suspected of child abuse. Psychosocial support to the families is the most neglected field.

Key words: Osteogenesis imperfecta, brittle bones, psychosocial support, parental support, preschool children.

Foreword

Children with osteogenesis imperfecta (OI) or brittle bones is a small and relatively unknown group. It is estimated that less than 300 people in Sweden suffer from this disease, and about five children with this disease are born every year.

This report include interviews with three families with brittle bone children between 1 1/2 and 7 years of age. The project has been supported by a grant from The Swedish State Inheritance Fund and is part of the project "Psychosocial support to families with brittle bone children".

The work has been carried through by members of the research group WRP International (Women Researchers in Play and Disability).

The English translation of this report has been effected by Kristina Millde and been edited by the WRP-member Mary Sinker, Evanston, Illinois, USA.

June 1990

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CONTENTS

I. INTRODUCTION

In Sweden about 5 children are born every year with the diagnosis of osteogenesis imperfecta (OI), i.e. brittle bones. As the handicap group is small, knowledge and experience of the disease and its consequences is very limited.

Parents who have a child with brittle bones mostly feel they receive poor support from society, especially as regards psychological and social services. Many parents consider it important to receive good information about the handicap and its consequences as soon as possible, i. e. when the child is a newborn. It often happens that the person in charge of giving the information says he has informed the families at an early stage but they have not been able/ready to accept it.

This is sometimes true, sometimes not. The parents need and have the right to receive good information at an early stage about their child´s handicap. There is no reason to believe that such information should effect the relationship between children and parents in a negative way. On the contrary. To have a permanent worry about what the child´s handicap means and what it can lead to in the future can strongly effect the relationship. A great deal is left to the fantasies and fears of the parents, which may have a bad influence on the child's self-image.

If the parents cannot understand information given immediately, the person responsible for the psychological support must wait until the family is ready for it. They also have to adjust the information so that the family can really understand it. It is important for a resource person for the child and the family to take into consideration the parents´ own questions and expectations. It is never easy to have a child with a handicap, and it is important that he who gives the information to the parents shows understanding of the family´s situation. It is the needs of every individual family that should guide the contribution from society, and therefore it is not possible to speak about a contribution equal to all. It must be worked out with regard to conditions and special wishes of each family i order to make the family ready/willing to accept it.

Today very little is written about children with brittle bones in Scandinavia, and also in other parts of the world. Early descriptions of "porcelain people" can be found in history, which shows that the disease is very old. During later years some new discoveries have been made, old treatments are questioned, and new are added. It is a field in progress even though a great deal is still unexplored.

Within the National Association for Disabled Children and Young People (RBU) there is a team working for the diagnosis group of osteogenesis imperfecta (OI), i.e. brittle bones. In this report we have chosen primarily to use the word brittle bones but sometimes also OI.

The Nordic associations for OI have edited folders and informational brochures about the disease. The most comprehensive work so far is a report from The Swedish Handicap Institute named "Children with brittle bones and their life situation" (Brodin, 1989). The report is based on a questionnaire sent to 24 families, and interviews parents in three families with children of 5, 8 and 13 years describing the family´s life situation.

1.2 Aim

The aim of this report is to describe what support three families with preschool brittle bone children have received and what they think they would need. The aim is also to increase the knowledge and understanding of OI. In addition to parents, the report is meant for professionals at obstetric departments, nurses, child care personnel and professionals in community based child care.

1.2 Method

The report is based on literature studies, articles and reports and interviews with parents. A survey of existing types of support for children with mobility impairment has been done. This report deals with three of nine interviews with parents done within the project. The nine families are all members of the National Association for Disabled Children and Young People (RBU) and belong to the diagnosis group of OI. The working group for OI within RBU asked the families if they were willing to participate in the project and all parents were positive. Their main concern was to inform other parents.

2. WHAT DOES BRITTLE BONES MEAN?

Children with brittle bones are a relatively unknown handicap group. The difficulties for the children and their families are often complex and the need for support is great. Experience and knowledge of brittle bones are very poor due to the fact that the handicap group is so small. The type of brittle bones referred to is not comparable to the kind elderly people suffer from, i.e. discharge of calcium in the skeleton. These children have a disorderly and incomplete bone development.

RBU have based their description on two main types of brittle bones: congenita and tarda.

OI Congenita is the most unusual type, and the child is born with evident symptoms of the disease. Some children are so severly effected by the disease that they die in the foetus stage or very soon after birth. Many of the children with OI congenita are born with unhealed or wrongly healed fractures.

OI Tarda appears later - often between the ages of six months and 2 years. OI Tarda exists in two forms: one more severe, giving many fractures and bad deformities in arms and legs, and another, less severe form.

There are different types of brittle bones, and in fact it is not sufficient to divide the disease into just two types. Within each main group you can find a number of varieties depending on the severity of the disease and when it appears. In this study, however, we have chosen not to investigate this but want to mention that there are many ways to classify the disease. However, congenita and tarda are considered the two main types.

It is interesting to mention the symptoms appearing in connection with the disease. The most evident symptom is the disposition for fractures. A slight push or a quick muscle movement can be enough to cause a fracture. The many fractures lead to deformities in arms and legs. The consequence is that, long term the children often have to use a wheelchair. Other symptoms can be blueish eyeballs, brittle teeth, a convex chest, short stature and, later in life, reduced hearing. Common to the different types of OI is a lack of minerals in the skeleton. There is also a shortage of a protein called collagen in the connective tissues. During the last few years the shortage of amino acids has been shown to have a vital influence on the appearance of the disease. The disease is hereditary, but it also occurs in families which have not had it before. This can be explained by a latent disposition or a genetic mutation. The disease cannot be cured.

3. RESEARCH ON BRITTLE BONES IN AN INTERNATIONAL PERSPECTIVE

At Children's Hospital National Medical Center in Washington, USA) a program has been designed for the rehabilitation of children and adolescents with brittle bones (Binder, 1984). The program was designed after noticing that increasingly more children survive today despite severe forms of brittle bones, children who previously died before birth or during delivery. The aim of the program is to improve the children's life situation and increase their quality of life. First of all the program is concentrated on reducing contractures and deformities, preventing weak muscles and reducing deformities in the lower extremities.

The program calls for qualified cooperation with the parents. In the introductory test four children between 3 and 11 years participated and the result was encouraging. By increasing the children's strength and mobility the children were able to participate in activities more appropriate to their age. The program stresses the importance of physiotherapists teaching both the parents of a newly born child and medical care professionals how to treat the child correctly i.e. sitting up to avoid fractures. In the program the parents get concrete advice and help with training (see appendix 1)

The results of the program are very positive. The children have increased their functional muscle strength and invigorated the ligaments in their legs. Their general condition has improved and their development and socialization are more age appropriate. The risk connected to the program could be an increased number of fractures, but with the help of physiotherapists and doctors the children's severe handicap can be considerably alleviated.

Helga Binder (1984) and her research team also found that the children are on an average IQ level or above, but they are often isolated because of their fear of fractures. According to Peter Byers (1988), professor of pathology and genetics at the University of Washington, this is not correct. He suggests that this is a misinterpretation, as the person who forms the opinion of the child often has difficulties keeping in mind that the very short person he is talking to in fact is a teenager. Today there is no support for the theory that intelligence genes have a direct connection to the collagen genes. The first theory is supported, though, by the researchers Glenda Shea-Landry and David Cole from the Department of Pediatrics at Dalhousie University of Halifax in an article published in 1986. The question of intelligence is not very important from a habilitation point of view, but it might be important, however, to support the identity development of the young persons with brittle bones.

An important question for parents of children with OI is is the unfounded suspicion of child abuse. Many parents are exposed to these questions and several articles mention this issue (Shea-Landry & Cole 1986, Brodin 1989). This is an important question for the families, who feel frustrated from the lack of help and practical information. The families' situation is very difficult from a social point of view, as the children are bound to make many visits to hospitals and have several operations. Shea-Landry & Cole suggest that today you must consider all kinds of treatment as an experiment, as no-one knows how to cure a brittle bone patient. This means that the parents must have the strength to cooperate in various treatments. Different types of injections as well as lazer treatment against pain are being used. For some people the treatments give certain improvement. Another question, stressed by these researchers is the fear about coming to a hospital with your child and meeting professionals who know nothing about OI and who, for instance, do not understand that the children must be handled in a special way. It is not difficult to understand, she says, that many of these children are overprotected, as it is not always easy to make other people realize that the children need special care.

All over the world there are associations for persons with brittle bones, their relatives and professionals working with OI. The most active countries are Canada, USA, Australia and England. The Canadian association for OI, COIS, (the Canadian Osteogenesis Imperfecta Society) have prepared written advice to accompany the child e.g. at visits to the hospital, to be put above the child's bed. The card should be placed at the head of the bed. The following points are important to consider, as per COIS. Ask the doctor to sign the card to make it more trustworthy. It might be a good idea to cover the card with plastic. Put a small card among the child's patient cards at the hospital. Be sure to keep an extra card in your purse. The advice is drawn up by Brenda Wylde and the cards are delivered free of charge from COIS to members. On the information sheet the following is written:

BRITTLE!

TREAT ME CAREFULLY!

I have OI and my bones break very easily. You must:

NEVER	push, pull, turn, bend , put pressure on or try to straighten my legs
AVOID	turning my head
AVOID	lifting my legs when changing pads
ALWAYS	place your hands under my bottom and push the pads under
ALWAYS	treat me with care, with soft motions, support my head, my chest and bottom clearly
ALLOW	my parents to be near at X-rays and other examinations

They know how to treat me

A problem that might occur is jealousy between brothers and sisters. A child who has a new brother or sister often shows jealousy as he/she does not want to share the parents with a new member of the family. The elder child often attacks the new little baby by teasing and giving little pushes and hard pats. This behaviour is quite normal. For a child whose brother or sister has OI, the situation is different as it is not permitted to show feelings in a normal way and give the baby these little "hate-love-pats". He cannot give the slightest little push without tremendous consequences. In addition to this the new little baby with OI needs a lot more attention and care than a new little baby normally does.

The parents´ feelings for the elder child become divergent as they easily consider him/her a risk to the child with OI. The elder child has trouble as the possibilites for expressing normal aggression and jealousy are limited. Eileen Edwards is a psychologist in "Early Childhood Development Complex", City of Knox, Victoria, Australia and she has worked a great deal with the problems of sister and brothers. The child who has a baby sister or brother easily regresses, i.e. returns to earlier stages of development to get more attention. The child may demand to be fed and starts talking baby language. The child can also show aggression towards younger children and become a problem in the interplay with other children (Edwards, 1979). To avoid difficulties that can give negative consequences for the child, opportunities to play with other children must be offered where the aggressive feeling can be worked out in a natural way through playing. For some children a punching bag might be an alternative, Edwards suggests. Make-believes of different types can also be helpful for the child. The parents can work actively to give the brother or sister a social life of his/her own outside home together with friends and in different play groups. To be periodically alone with one of the parents and have all the attention can also be comforting for a child who has a brother or sister with OI.

It is evident that the child´s disease causes not only medical problems but to a great extent also effects the child´s development and emotional life. For a child with OI the functional impairment in many cases leads to developmental obstacles and delays because of reduced mobility - often due to fractures - and not least the great number of separations from the family. Lynn Stephen (1983) tells about a little Eskimo girl, Nippi, whom she had followed for some years. Below is a profile of this little girl´s life.

Ever since Nippi was 10 months old she has had fractures. At the age of 20 months the fractures occurred very often. Therefore she had to visit the hospital many times, and as the hospital was far from home she was left there. As soon as the fractures were healed and she was about to leave the hospital she had a new fracture. Eventually a fosterhome close to the hospital was found. Nippi's second year of life was divided between two worlds - the home and the hospital. As Nippi was an Eskimo she had difficulties understanding the different languages and therefore her language development was very delayed. The separation from her biological family had a very negative effect on Nippi, and she had terrible tantrums as her tolerance level was very limited. When Nippi´s mother came to visit her at the hospital after 3 1/2 months Nippi did not recognize her. She had gotten used to calling almost all the women who took care of her, mother. At the hospital the personnel used photos to try to help Nippi recognize her mother.

Nippi spent three birthdays at the hospital. When her development was in the stage of expanding from an egocentric world she lived a secure and secluded life. She was not aware of the sounds from outside - buses and cars. She could not see and recognize the sky, the trees, the birds or the butterflies. How do you teach a child who has never been outdoors about the rain and the snow? The professionals at the hospital then started to work with play as a therapeutic model - when it was raining outside they played with water - when it was snowing they brought in snow. Through playing they succeeded in helping Nippi show her feelings and take on different roles when playing. A child learns about the world through playing and develops its abilities. The equipment was adjusted to Nippi´s needs to encourage her to investigate the environment. She refused to play with modelling clay. Of good help in the therapeutic work was another child, Matthew. He showed Nippi the way. Matthew was very interested in food, and with the help of the food, to give and take, for instance, he taught Nippi and made her interested in food. They learned to play together and that helped Nippi´s development.

Lynn Stephen, who works at Children´ Hospital, Winnipeg, Canada, finally questions if Nippi´s case could have been handled in a way that was better for the child. For example, would it have been possible to have a therapist come home to help the mother? In Nippi´s case there were several difficulties. One was the long distance to her home from the hospital. Another was the expectations on Nippi from her family. The doctor visiting her home noticed that she behaved and was looked upon as a baby and very little was expected of her. She was loved and received a lot of attention, but no-one expected any development mentally or socially. A special program was then worked out and the parents were provided with suitable equipment for Nippi. Today she is ten years old and lives at home in her normal environment with support from specialists. She has developed very well, despite her difficult start in life.

Adolescents with brittle bones have thoughts and reflections like every other young person. However, they often reflect about their situation; of being in a wheelchair, relationships with the other sex and sexual relations. It is important, Shea-Landry and David Cole suggest (1986), that the different handicap organizations pay attention to adolescents, and help them to form an identity as adults.

In The Times, Health & Science (August 11th, 1988) there is a report that among other things deals with treatment of OI during childhood. It is stated that probably 20-50,000 people in the world have brittle bones. A common type of treatment is to strengthen the bones in the arms and legs with pins in order to reduce the number of fractures. A stainless steel pin is simply entered into the bone. This method is also used in Sweden. Dr Lawrence Rinsky, head of the orthopedic and rehabilitation department at Stanford Children´s Hospital, California, is against chiropractical treatment of brittle bones. He does not believe in external influence as neither chiropractics or the use of orthoses can change a spinal deformity. However, the chiropractician Barbara Ross in Campbell, California, suggests that she has noticed positive changes in patients with OI. To conclude, there is a great uncertainty about the value of different treatments today, and as Byer (1988) claims research still is in an experimental and initial stage. Byer, who has worked with parents, praises their attempts to find new ways suitable for their children. He has said:

"Everyone of you who is a member of a family affected by OI will know more about OI than most of the doctors you see" ... "You are your child´s best advocate. It´s important that you become well-educated and learn how to deal with doctors and other health professionals". (The Times, Health & Science, 1988).

4. CHILDREN WITH BRITTLE BONES AND THEIR LIFE SITUATION

A project aimed at making an inventory of the need for technical aids and adjustments of technical aids for children with brittle bones, and describing the families' life situation has been carried through by the Swedish Handicap Institute. This study shows an extensive shortcoming as regards the contribution from society to the families (Brodin, 1989). At the time of the study 27 families with children and adolscents under 18 years with brittle bones were members of RBU. 24 of these families were willing to participate in the project, and answered a questionnaire. Three families were chosen for in-depth interviews.

The study shows that there are many unsolved needs for technical aids. It is difficult to get technical aids working in daily life. On one hand the parents complain about the technical aid service, and on the other there are concrete needs to have aids designed, which means new development as well as special adjustments of existing technical aids.

The parents expressed that they receive poor information about technical aids. When the parents were asked if they had received the technical aids they needed several parents answered that they could not answer that question, since they did not know which technical aids existed.

The parents are worried about the great lack of knowledge about children with brittle bones. A recurring problem is how to disseminate information to those who work within the technical aid and health care
field. Information and education about technical aids and the implication of the handicap is wanted.

The families have received very little help in having their housing modified. They have felt very unsure of how to act in this matter, and have therefore often had to solve their problems by themselves. Sometimes this has resulted in bad solutions which have not given a satisfactory function in the long run, but have had to be redone later. One of the families got a swimming pool as a housing modification after having the issue discussed in the Supreme Administrative Court in April 1986. Before that the question had been dealt with in many instances and had been rejected. The decision can be considered precedential and gives other families the possibility to claim economical support for house modifications. The training of muscles in a swimming pool is one of the best ways for those who easily break their arms and legs.

The parents' concern about the child getting fractures is all-pervading and certainly a reason why the children are often lonely, i.e. without friends. Play is essential and gives opportunities for development on many levels. Half of the parents admit that they are often worried when their child plays with other children; the other part of the parents admit that they are worried sometimes. The parents are aware of the fact that their concern may hold the child back. There is a risk that parents living with a constant worry for their child getting hurt may delay the child's development. It is a difficult situation for the parents, and good advice from "experts" does not always help. The parents must find out for themselves how far they can let their child go. The child's maturity and awareness of the handicap will show the parents the way.

The parents expressed the need for an early diagnosis. Of the 24 families no fewer than eleven have been subjected to suspicion of child abuse. In two cases the social authorities have been involved. In one case the child was removed to a fosterhome for a period of a month. For those reasons it is important to make the diagnosis early. Some parents expressed a dream of a center where families with brittle bone children could come for diagnosis, treatment, operations, trying out technical aids and psychological support. What the parents really ask for is a professional team with competence from the different areas involved.

5. SUPPORT FROM SOCIETY FOR CHILDREN WITH MOBILITY IMPAIRMENTS

Families with a child with a handicap has the right to support and help from society. This chapter focuses on information about different types of support available in Sweden and where to turn for more knowledge. In Sweden the Social Office in the district thw familiy lives, in compliance with the Social Act of Welfare (SOL) is obliged to give advice and help.

5.1 Practical and financial help

In Sweden every family who has a child with a handicap does have certain right to obtain allowances from the government and from the community for housing, house modifications and care. Other services are also available such as help at home, transport service, technical aids, and free medical care, medicine and health care. Below the benefits are listed.

Housing allowance

Housing allowance from the state and the community can be applied for by families with children. The amount granted depends on;
- income
- costs for housing
- other allowances
- the number of children

In some districts community based assistance for handicapped is provided. The aim is that the family shall be able to choose accomodation that fits their child's special needs without raised costs.

However, certain conditions must be fulfilled;
- the family must be entitled to housing allowance
- the flat/house must have a good standard and be equipped to function well for the child
- extra costs for housing because of the child's needs

Allowance for housing modifications

This allowance is meant for families who need to modify their flat/house to adapt it to the child's handicap e.g. build a ramp at the entrance, remove thresh-holds etc.

A good standard of the housing is a prerequisite as well as some fundamental conditions with regard to the handicapped child. This is a government allowance not related to income.

Care allowance

The family can apply for care allowance if the handicapped child needs extra care, is under 16 years of age and lives at home. Full or parttime care allowance may be obtaibned depending on how much extra care the child needs. Part of the allowance is tax free. A doctor´s certificate is required. If there are more than one child with handicap in the family a care allowance may be provided even if each childs handicap individually does not entitle to a care allowance.

If the parents do not live together and have divided the care for the child, the allowance can be divided as well. The parent must have lived in Sweden for one year before care allowance can be provided.

Holiday care allowance can be payed out when a child, normally living away from the family (e.g. in an institution), visits the home temporarily. The visit, though, must last for at least 10 days.

Home care allowance

In families who have a child with a handicap who needs permanent supervision and care at home some communities provide a home care allowance. A doctor´s certificate is needed to obtain this service.

Help at home

Some communities have child care professionals, who relieve parents caring for children with a handicap. The amount of time for relief is decided by the Social Office.

Transport service

Permission for transport service is provided to families who cannot travel in an ordinary way because of the child´s handicap. The parent and the child can go by taxi or special vehicle, depending on the degree of handicap.

Free medical care, medicine and health care treatment

For prescribed medicine everybody who lives in Sweden pays a limited fee, even if several prescriptions are provided at the same time. All doctors have a list of severe or longterm diseases that permit medicine free of charge.

A special card for medical care, medicine and health care treatment is obtained from the doctor or at the pharmacy. After 15 treatments within 12 months a "free-card" giving medical care, health care treatment and medicine free of cost for the rest of the 12 month period is received. If there are more than one child under 16 years in a family the childrens treatments are added on the same card. Health care treatment means physiotherapy, auditory care, occupational therapy etc. This is obtained through a letter of introduction from a doctor.

Technical aids

There is at least one Technical Aid Center in each county council where technical aids for mobility and activities in daily life are fitted, adapted and distributed. At hearingcenters, sight-centers and orthopedic departments technical aids are also fitted and distributed. Such centers can be found in most county councils. Prescription of aids is made by different professionals, depending on the type of technical aid.

In Sweden technical aids are free of charge and the family may keep them as long as they are needed. Certain disposable articles such as diapers, syringes and bandages can also be obtained free of cost.

5.2 Habilitation

The habilitation of the handicapped child is the responsibility of the country councils in Sweden. Habilitation involves medical, educational, psychological and curative support to families of children with handicaps. The habilitation program is individually adapted to the needs of each child.

The family gets in contact with the habilitation team when the handicap has been discovered. Both the child and the parents are entitled to support and help during the child´s whole growing period. The county council´s habilitation centre for children with mobility impairment is tied to a child care clinic or special treatment centers. A district team with a physician, physiotherapist, preschool teacher, social worker, speech therapist, psychologist etc. work as a team at the habilitation centre. The habilitation centre is responsible for for medical investigation, physiotherapy, speech training, councelling and educational programs etc.

Toy Library /Lekotek

For children with a handicap the toy library can be of great importance. Today a toy library often is included in the services available from the habilitation centre. Together with the parents the professionals at the toy libraries make a choice of toys that are aimed at encouraging the child to train different functions. An educational program is often offered which continually is adapted to the progress of the child.

Preschool and leisure time homes

The preschool in Sweden consists both of day care centers and part time groups. For the child's overall personality development and support to the family enrollment at a preschool or a leisure time home is of great importance. The social part of the preschool and the leisure time home is most important for the child with a handicap.

Parents can claim modifications of the preschool-program offered to suit the needs of their child. This may involve the need for extra professionals, adjustments of localities, decreasing the size of the group, etc. For children who cannot attend an ordinary preschool there are special groups, or in certain cases special preschools mostly run by the county councils.

The compulsory school

Most pupils with a handicap attend ordinary local schools. The school is responsible for making attendance at school possible and meaningful for all pupils. Extra support is often needed for children with handicaps. This might mean personal assistance, technical aids and adjustment of localities. Pupils with mobility impairment, their parents and teachers can also turn to regional consultants for advice at the county school board.

The different handicap organizations concerning children and adolescents have an important function as support for each handicap group. A special working group for children with brittle bones has been formed under RBU.

6. INTERVIEWS WITH THREE FAMILIES

6.1 Interview with Edward's family

Edward had fallen off a small box and broken his shoulder. We therefore had to postpone our meeting with his family; they had been visiting his grandparents and could not return home before he was able to travel. This is quite a typical situation in the family of a child with OI. Edward´s family consists of mother and father, a two year old sister and Edward who has OI and is seven years old.

Support from the Community

During her pregnancy Edward´s mother noticed that he stopped moving in the seventh month and she began to worry. The staff at the women´s clinic told her not to worry and so did her friends. This was her first baby and she had no previous experience to compare with but remained very concerned. The delivery was very difficult. The baby was too low and a Caesarean section had to be ruled out. They considered using suction but decided against it. This was fortunate as the top of Edward´s head completely lacked bones. Edward was born with many fractures. He was immediately taken from the mother and she realized that something was very wrong. Noone, however, told her about what might be the problem.

Edward was born in the evening and eventually his mother fell asleep but in the middle of the night was woken up to answer numerous questions, still without receiving any news about her baby. Edward was born in one hospital but transferred to a different one the following day. The parents were only advised that Edward would probably die from shock within 24 hours. The doctors therefore suggested that the parents should not come along. In despair the mother then decided to go home in spite of her large incision. The next day the staff at the hospital asked her to return which she did. She felt that the staff as well as fellow patients avoided her and she requested a private room. ´´You must get used to other babies´´, she was told. The mother felt as if she had a contagious decease.

The next prognosis arrived:
Edward might live two more weeks. The parents decided to spend this time with Edward. They were transferred to a different hospital where they were treated much better. Edward was kept in an open type of incubator. There were anxious moments every day upon arrival before they knew that he was still alive. Occasionally he had been transferred to a different room which created additional trauma until they found him. Approximately two weeks passed without any news. They asked if Edward might have skeletal cancer but received only vague replies. Finally they got the word

that Edward had OI but the information about it was very sketchy. A baby with OI had not been born at this hospital for 15 years. The parents were invited to be a ''living example''at a lecture for medical students and received some information that way.

Finally a doctor decided to take care of this family and started to visit the mother each day before going home. He kept in touch with them on a regular basis even after they moved home. Carrying Edward was difficult even in a babylift. The parents lived in a building without elevator and decided to move to a bungalow. For three weeks during moving time they had the assistance of a nurse which was very helpful.

A child who is hurt and cries stirs our emotions and our instinct is to lift him up and console him. To not be able to do this with Edward has been most difficult for his mother. Edward's life expectancy was extended another year and a half and the family could relax for a while. Time passed and they began to worry again. They have often been trown between hope and despair. At one time the mother read Edward's file and found out that she herself suffers from oral galvanism. At the time she did not know what this was and was very shocked. She learned that she has a very high level of mercury in her body and was advised to replace her fillings. This process which is still going on, is exceedingly taxing. Edward also suffers from oral corrition and the mother suspect this to be the cause for his OI.

She sometimes, against better judgement, blames herself for Edward's desease. Edward had thirty major fractures before the age of three at which time they stopped keeping track.

Medical support

Edward received injections during a short period but this caused his personality to change so much for the worse (he became drousy and listless) that the treatment was discontinued. There was a severe crisis at the age of one when he caught whooping cough but against all odds he came through all right. They get a different doctor at each visit to the hospital emercency department which causes problems since they must go through the entire case history every time. At the time of an emergency one does not want to waste a moment. Nowadays they go there only when absolutely necessary.

Edward has had major surgery a few times. On one occasion his femurs were severed, and a steel pin inserted. Later on, when they discovered that he suffered from oral corrition (a topic subject to much discussion in this country) the operation was repeated and the pin replaced with a titanium one. Presently a third operation is considered. The mother feels that they have been mostly well treated at the hospital except at the time of the delivery when the treatment was beyond criticism.

Psychosocial support

The mother has a ''child care allowance'' (money paid by the state to people who take care for sick or disabled children in their own home) and has recently been given transportation service. The mother keeps repeating that they wish to live as normally as they possibly can. Respit service has not been discussed. During the first three years of Edward's life they did not want to leave him with anyone else. The grandparents have not been able to help out much for various reasons.

The staff at the Child Health Care Centre noticed that Edward grew, started to crawl, learned to sit up and developed well. He also did not have the characteristic blue eyeballs and new speculations ensued. Perhaps Edward did not have OI? That was a difficult time with much worry and uncertainty. Nowadays, when the risk for further fractures is so much smaller, he can usually take part in the family excursions. He is very social and has many friends.

For the last two years Edward has been attending kindergarden. When he first met his personal assistant she expressed herself in a way that upset the mother very much. She commented on his walk and appearance , calling it strange. This was very indelicate and they felt hurt. Later on another assistant took care of Edward and he will keep having his own assistant when he starts grade one. At that time the parents will again have to supply the entire case history. They wish there was some kind of reading material to provide these people with. It is hard to explain everything from the beginning each time.

No psychological help of any kind has been offered this family. Noone has asked them how they are and how they feel about future. They also have not been offered any case management help but on the other hand they have not requested this kind of help. As stated above, they would like to lead a normal life if at all possible. They wish to manage on their own as they used to do. Edward and his mother have ´´sad talks´´sometimes and afterwards they feel a little bit better. Edward and his parents have cried much together and sometimes ask themselves if there is a purpose for their struggle. They stick together through the tough times and have survived the crisises. The mother started to paint, until then an undiscovered talent. She thanks Edward for this and by painting she gets rid of tension and at the same time feels that she is developing as a person. This is one way she can get through a crisis.

Awareness of the Handicap

Edward has started to notice himself and wonders why he is different from other children. ´The sad talks´´with his mother is one way he can express his thoughts. None in the family hides his feelings and they have become very close from speaking candidly to each other. When things are really bad even little Edward wonders if staying alive is worth the effort. It is terribly tough some days but then his survival instinct forces him to go on. In some ways he is stronger than most, yet fragile.The parents have not overprotected Edward. He has been allowed to move and play at his own pace. He is a very lively little chap and he probably feels better without many restrictions. The OI Association provides support by bringing together people with similar experiences and problems. These people would not get together anywhere else. The family only wishes that a wider variety of questions might be discussed there.

Edward´s development has brought about hopes for the future. He keeps improving and has many times surpassed all expectations. Being very short in stature is, however, a serious handicap.

Daily Activities

As stated above Edward is very lively and also very curious. He moves around quickly in his wheelchair, somewhat less so on crutches. He can take part in many games and activities with other children. I some respects he handles many situations better than healthy children. It is unbelievable that this is the boy who was not supposed to survive the first 24 hours after birth.

6.2 Interview with Paula´s Family

Four year old Paula lives with her mother in a city in the south of Sweden. We met at the hospital where Paula was staying due to a femure fracture. The mother spends most or her time with Paula, a. alert little girl with a sparkle in her eye. The mother lives alone but Paula´s father has a good relationship with his daughter and spends some nights with her at the hospital. Normally she also visits him at his home on a regular basis. When Paula was born there was no sign of OI. A neighbour noticed Paula's blue eyeballs but some babies have that and the mother just thought it cute.

Support from the Community

Paula did not learn to sit by herself until she was seven months old and then with much pain which made her scream loudly. When the mother consulted a doctor at the Child Health Care Centre she was told that some children prefer to walk directly without going through the stage of sitting up first. The mother had to leave with this explanation. It was later discovered that three vertebrae in the spine were totally crushed and several nerves squeezed.

Three weeks before Paula´s first birthday she fell and had her first fracture of the hip bone. The hospital staff suspected that Paula had been abused but the X-ray in combination with other research proved that this was not the case. Paula has had two additional hip bone fractures and some minor accidents probably resulting in cracked bones. On a few occasions she has fallen on her bottom causing further compressing of the spine and now the entire spine is affected.

Medical Support

At one time a pin was inserted in one of Paula´s hips in order to make it stronger. Bone and skin samples were sent to laboratories in England and France but according to the results there was nothing wrong. Paula received about thirty injections of cibacalcin three times weekly during one time. Before this treatment started Paula´s doctor had suggested an experiment with hormones. The mother turned it down when she could not get an explanation as to exactly what kinds of substances were to be used. Later on she aquired a satisfactory description by the ´´habilitation doctor" and the treatment could start. At the time of the first fracture the mother was dealing with a clinic at the hospital where the staff treated her very indifferently. They directed her, however, to the orthopedic clinic where she has received much help. Through the habilitation team the mother met many efficient people of various professions such as case managers, doctors physiotherapists etc.

Psychosocial Support

Paula´s mother receives a ´´childcare allowance´´ from the state and has been offered respit service. She feels, however, that she wants to manage the situation by herself without ´´taking advantage of social services´´.She has also been offered daycare for Paula but she is afraid to let anyone else take care of her. For some time now Paula has attended a play group with other handicapped children. Grandma babysits sometimes, but for extended periods the mother is alone with the responsibility. She has not had anyone to talk to about her situation. When she talks with neighbours and friends it is mainly about Paula, her desease and development. Hardly anyone has asked how the mother is. She seems to believe that one must manage on ones own and not bother others with one's problems. She often cries from lonelines and she has had very little sympathy from her own family. ''It´s typical of you not to be able to produce a healthy baby´´, her father once told her. This was very hard to hear right after getting the bad news about her child's OI.

One nurse and also to some degree other staff at the habilitation centre together with the contact person for the OI Association provided the best support. She has a good relationship with her neighbours but noone is her own age. She is only twentyone years old. The case manager at the habilitation centre has been the one person to count on and consequently her best support.

Awareness of the Handicap

One nurse at the habilitation team informed Paula´s mother about an association for families who have OI children and a person from this association contacted her. The first time they met they talked for almost three hours about the desease, what to expect, reading material, camps etc. Since then the mother has gotten very little out of this association. She knows of no other children with OI in her part of the country.

Paula´s mother has stubbornly taken on the role of ´´the good mother´´. In order to compensate Paula for her handicap as well as dealing with her own conscience she has bought presents and become, in her own words, ´´the little tyrant´s slave´´. Even very young children learn to get their own way quickly . Mother fetches and helps. Paula can walk short distances, although with a limp,but also uses a wheelchair.

Paula does not like when grown-ups call her "the poor little thing" and some even give her hand outs. In the toy shop and the kiosk they are sometimes not allowed to pay for their purchases. This misguided kindness hurts the mother and makes her even less inclined to ask for the assistance she is entitled to.

Paula's mother is very young and needs the opportunity to socialize with her peers and also a chance to meet a new man. She asks herself who would want her, the mother of a handicapped child demanding most of her attention. She sees no positive answer to that question and does not feel like trying. At least not yet. She realizes, however, that in the long run Paula would benefit from having a mother with a life of her own. A sacrificing mother would become a burden eventually.

This mother has not dealt with her crisis but she is starting to realize that she must be prepared when Paula gets older and need to develop a positive idea of herself and her handicap in order to accept herself the way she is. The mother knows that you get stronger from exercise and believes that Paula will get better as she grows. She is fairly mobile now and the mother is optimistic.

Daily Activities

Paula is now attending a group with other handicapped children and will shortly be transferred to a different group in order to meet with school age children. She gets pre-school classes and the social interaction with other children which is just as important. She will have a personal assistant in this new group. Paula can take part in many activities but she must be careful. She is alert bur her language is poor. Her mother, however, understands her. Paula has started to take notice of herself and is beginning to understand that she is not like other children. This is very painful for the mother to watch.

6.3 Interview with Emma's Family

One and a half year old Emma lives with her mother and her older brother in a small town in central Sweden. The mother has OI herself and knows what is involved. She recalls her own childhood when watching Emma's growth and development. With time her own spine has become compressed and nerves are being squeezed and she is in much pain. As a result she had to quit her job. Now she gets her income from a medical pension, a housing allowance and the child support payments from the chidren's father.

Support from the Community

Emma's was OI diagnosed immediately after birth. An X-ray before the delivery disclosed that one femur was slightly curved. Directly after birth Emma was placed on the stomach of her mother who immediately noticed the baby's blue eyeballs. She realized what this meant.

When it was time to leave the hospital the doctor who had treated herself as a baby came to see her along with some colleagues. He asked to see Emma's eyes which made the mother afraid that she might not be allowed to leave the hospital. The doctor, however, was only there to familiarize his colleagues with OI, of which they knew very little.

Medical Support

Emma has had no special medical treatment except the normal care for fractures etc. There has been three major fractures , one of theshoulder and one of the metatarsal bone and one of the lower part of the leg. The attitude towards her at the closest hospital has been very bad. The staff behaved indifferently and paid little attention to her opinion in spite of the fact that she has OI herself. She does not want to go back there and prefers the hospital in a bigger city further away. The staff there is knowledgable and friendly and, furthermore, the doctor she trusts is there.

Example: A few weeks ago Emma broke her leg which was put in a cast at the hospital in spite of the mother trying to prevent this, knowing very well what would happen. Sure enough, the pressure from the cast had caused a wound and had to be removed after three and a half weeks. A short time later one discovered that the foot was turning sideways. They told her at the hospital to be grateful that Emma could use the foot at all. Very disappointed, the mother went home. She got in touch with her "old" doctor who promised to see them the next day at the closest clinic with all their files. He suggested an exercise programme which they have followed religiously and the position of Emmas foot is already much improved as a result of this.

Psychosocial Support

Six months after Emma's birth the mother got in touch with a physiotherapist at the habilitation centre and she arrived with a high-chair and and a stroller. She also did some exercises with Emma a few times but decided that Emma was well enough to be looked after by her mother. She also told the mother about the Association. Emma's mother has not communicated with anyone else suffering from OI, neither children nor adults. She received an invitation to a camp from the Association, but cannot afford to go. She would, however, like to have the chance to meet with other people afford to go. She would, however. like to have the chance to meet with other people in the same situation as herself. Her doctor once helped her to apply for Child Care Benefits but the application was rejected at the Social Services Office. They did not consider her to have additional expenses as a result of Emma´s desease. The doctor has promised to make another attempt at it.

The mother has not been contacted by a case manager from the habilitation centre nor by any other authority. The above mentioned doctor is the only person who has given her any kind of practical help. She has not requested respit service. The children's father is supposed to have them every other week-end and when it in fact happens this is the only time the mother gets to herself. Her own parents have helped out on special occasions but these are rare. Her sister and a cousin are sometimes available to talk to but neither a psychologist nor a case manager have offered support or advice. She has not even realized that such help exists but feels that it would of course be very nice to have a sympathetic person to talk to.

Awareness of the Handicap

The mother tries not to overprotect Emma. She remembers well how important it was to try things out for herself and to discover her own abilities and limitations. Grandmother has a tendency towards over- protection. Both Emma and her other find it tiresome to hear all the ´´watch out´s´´ and ´´be careful´s" Emma's brother goes to a daycare centre and for some time Emma has joined him there. The mother, however, is considering keeping Emma at home because she worries about Emma getting hurt by the other children. The mother did not have any fractures herself until she was the same age that Emma is now. When Emma recently broke a leg the doctor told her that this was to be expected. The mother thinks that Emma perhaps has entered a stage where she is more fragile and needs extra attention. She sometimes worries about Emma's future but at the same time she feels that Emma eventually will know her own limitations.

Daily Activities

Emma is very mobile which enables her to take part in many activities at the daycare centre. She sometimes plays rather wild games with her brother without getting hurt. Other times a small fall on the floor causes a fracture. It is important for Emma and the people around her to learn to manage the situation. A ground floor apartment would make things very much easier for this family.

7. SUMMARY AND DISCUSSION

The intention of this report is to describe what support our society has to offer parents of children with brittle bones. The three studied children are between one and a half and seven years old. They are three of the nine children whose families belong to the OI group within RBU.

Only one of the three families interviewed knew at the time of birth that their child had OI. Emma's blue eyeballs showed that she had the desease. Because her mother also has OI it was easy to diagnose. In one of the families the delivery was exceedingly difficult and Edward was removed from his mother for examination it was. She had been worried during the pregnancy since the seventh month because the fetus did not move much but everyone told her not to worry. The third child in our study, Paula, showed no symptoms whatsoever of OI and when a neighbour pointed out her blue eyeballs the mother only thought it looked cute.

Edward was born with numerous fractures and missing skull bones. He was in critical condition and the hospital staff was not hopeful about his survival.When he was moved to another clinic during the night the mother went home as he was not expected to live through the night. The next day she was called back to the hospital but staff and fellow patients avoided her. Soon Edward was expected to live another two weeks and the parents decided to spend that time with him. They did not find out what was the matter but started their own research. Perhaps he had skeletal cancer. Later they were advised that he had brittle bones and that it had been 15 years since a child with OI had been born in that hospital.

Paula was seven months when her mother visited the child care centre, concerned that she did not sit up yet. It seemed that Paula was in great pain and she screamed lodly. The doctor advised the mother that not all children sit before they learn to walk. The mother was left with this answer but kept on worrying. Before her first birthday Paula had her first fracture. When they arrived at the hospital child abuse was suspected but after an X-ray OI was diagnosed.

Parents of handicapped children often complain that their worries have been ignored. Noone seems to take them seriously.

Medical Support

Edward received hormone injections during a short period but his personality changed and he became drousy and listless and the treatment was discontinued. His parents feel that getting a different doctor at each visit to the emergency department at the hospital is a big problem which creates the situation where much unnecessary explaining and even the entire case history must be repeated. Edward has had several big operations. On one occasion a steel pin was inserted and later when it was discovered that he was allergic to steel, the pin was replaced with a titanium one. These days they feel well treated at the hospital but at the time of the delivery the staff was rather awful.

Emma has had no special medical treatment except at the time of fractures. The nearest hospital is very unsatisfactory and the mother feels that they treat her indifferently there. The staff is not interested in the mother's opinion in spite of her own experience with the desease. Emma is, however, very well taken care of at the big city hospital where she is looked after by her mother's old doctor. Paula has had one hip strengthened and has also received thirty some injections of cibacalcin.

Psychosocial Support

Edward's parents strive to live as normally as possible. This means that they don't ask for respit service, wishing to manage on their own. There is also the fear of letting someone else take care of him. Their own parents have for various reasons not been able to help out. Edward has attended pre-school since he was two and has many friends. He manages better and doesn't have as many fractures as earlier. When he started preschool the parents were shocked to notice how little the personal assistants knew about handicapped children. Edward's mother recalled her first meeting with an assistant who commented aloud about Edward's appearance. Her incredible tactlessness hurt Edward as well as his parents. Today Edward has another very good assistant. The parents wish there was some informational reading material about OI which would save them from having to do all the explaining to everyone. Although they want to live as normally as possible they feel that noone seems interested in their mental state. They have cried a great deal together and the strenght of this family is that they are able to communicate and cry with each other when reality becomes too harsh.

Emma met with a physiotherapist when she was six months old who treated her a few times but then decided that the mother could do the exercises with Emma who she considered comparatively healthy. Emma's mother is rather lonely and would like to meet other families. It is difficult for her, however, to go to camps and courses for lack of funds. She has never taken advantage of respit service or a baby sitting service. Emma's father takes her every other week-end during which time the mother can relax. Occasionally when she has a serious problem her own parents help out but this help does not come automatically. She also has a sister and a cousin who she can talk to about acute problems. Emma's mother has had no support from a psychologist or a case manager and she feels it would be of great help to talk to someone sympathetic.

Paula's mother is twentyone and single. She has not had anyone to talk to about her situation. As far as possible she wants to manage on her own and not use the social services. She has turned down respit service and also daycare centre for Paula because she is afraid to let anyone else take care of her. Nowadays Paula is attending a play group with other handicapped children. The mother is very lonely and has had little support from her own father or mother-in-law. Her father's comment about producing an unhealthy baby was hard to take. A nurse and a case manager at the habilitation centre have been the most helpful people for Paula's mother. Although she has a good relationship with her neighbours she misses friends of her own age to socialize with.

Awareness of the Handicap

Edward has started to think about himself and what makes him different from others. The family has "sad talks" and this is their way of expressing their feelings. Everyone in this family talks candidly and show his feelings. Certain days are more difficult and they feel like giving up. Other days things look brighter. The parents have not overprotected Edward and he is allowed to move about and play at his own pace. He is very lively and he knows what he can manage and is developing an awareness of his handicap. There is hope for the future in spite of the purely physical problems, for instance, his exceedingly short stature.

Emma's mother tries to avoid overprotecting her. Having OI herself helps her to realize how important it is to test one's own abilities. Grandma tends to overprotect Emma and keeps telling her to watch out and be careful. This has become tedious. Emma now goes to a daycare centre with her brother but the mother is considering keeping her at home worrying that she might get hurt by the other children. Of course the mother also wants Emma to be able to live like other children and feels that she should discover her own limitations.

Paula's mother has taken on the role of the "good mother" and gives her presents.

This has become a problem and the girl takes advantage of the situation demanding more all the time. They have met many ignorant people in stores and other places. Misguided kindness can be very insulting. For instance, the time they were told to not pay for toys in the shop. Intended as a kindness, perhaps because the mother is so young, it shows an outmoded way of thinking and was insulting in this case. In our opinion it is incredible that this way of thinking still exists in our society. Paula's mother has not dealt with her crisis and it remains like a threatening shadow over her. She is very aware of the fact that she must deal with her own feelings in order to have the strength and support that Paula will need in the future.

In conclusion we can establish that the parents' situation is exceedingly difficult. It is of course important that the children can move around and play together with their peers but it is not hard to understand that they continuously worry and easily become overprotective. They are fully aware of what might happen and the problems that can ensue. A happy medium is hard to reach. The poor psychological support provided these parents is strikingly apparent. It has not become policy to offer the parents psychologists or case managers; instead the community's resources have been focused on the physical habilitation of the children. The family is not looked upon as a unit although, these families are more likely than others to be very close knit. Another question that has arisen is how information might be distributed and the level of knowledge raised among those who work with these chidren. All the parents have met many inconsiderate, ignorant people and, in some cases, with terribly shocking attitudes.

The parents have described how the children often take advantage of their situation. We want, however, to stress the fact that this is the case not only with disabled children. Many healthy children and adults take advantage of situations when possible to get out of doing certain things if they can get someone else to do that instead. We can, therefore, not make any generalizations about disabled children based on our findings. The parents are very much aware of the importance of giving their child a positive picture of himself and his handicap but even in this task it is desirable to give them support when they feel insecure. To increase the psychological support offered these families is of utmost importance. We realize that the information available about children with brittle bones is very limited and that this is due to the fact that this group is very small. This however is not allowed to be an excuse for not giving these families the support they are entitled to. On the contrary these parents are probably more in need of assistance than others just because they are alone in their worry. The parents have many practical problems to deal with and most of them are often alone and feel abandoned. The need to have a sympathetic person to talk to is great and in order to facilitate the habilitation of the child it is desirable that support is offered the entire family rather than the child alone.

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