

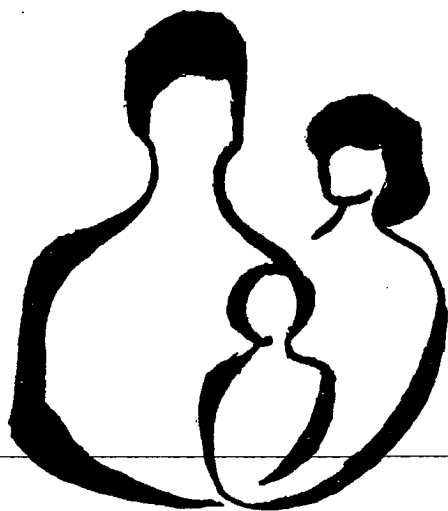
When we are parents of a disabled child



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Edited by

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A FEW WORDS ABOUT THE HANDBOOK.

This small book was prepared for parents raising disabled children. It is called a „handbook” because the persons engaged in its formation, parents and professionals, aim to impart their experience with the hope that it will help families with a handicapped child to understand their situation and will facilitate control of their child’s development.

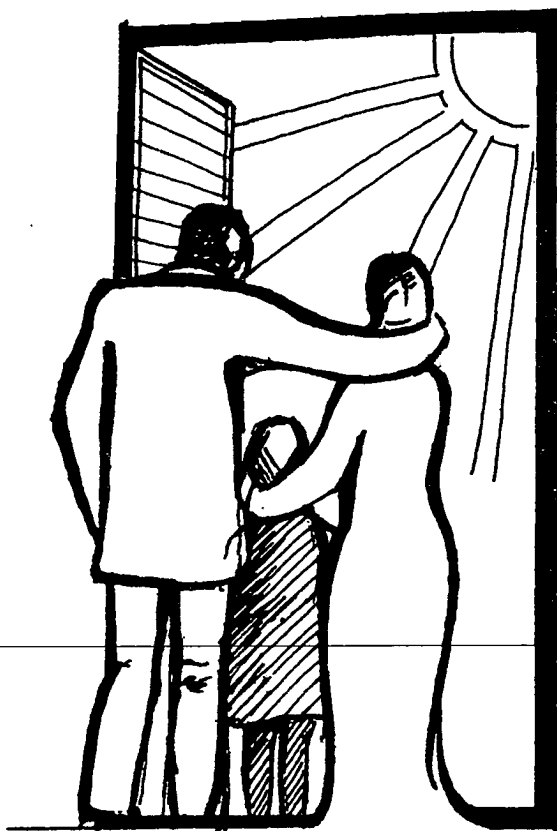
It consists of two parts. The first one entitled „Parents – to parents”, includes the letters of Polish, Ukrainian, and American parents of disabled children, who share with the reader their feelings and experiences and try to give concrete advice. In those letters you will find your very own anxieties and joys as if reflected in a mirror. You will realize that you are all one single family. In the second part, „Professionals – to parents” an effort was undertaken to show the problems of families raising disabled children from the point of view of scientific research and achievements in the fields of psychology and pedagogy. You will no doubt find that the same problems are discussed, but while the first part has a more emotional approach, the second part deals with the subject more rationally.

Let’s make an effort to look at your disabled child’s development from both of these perspectives.

The editors.

Part I

PARENTS TO PARENTS



A LETTER TO A HANDICAPPED CHILD'S PARENTS

The fact that mother has given birth to a handicapped child is for the parents a very hard experience. The parents should, as early as possible, consult an expert doctor. However, the first contact with an expert help, with an institution, very often produces stress with the people. So, an invitation to taking advantage of the work of an early intervention centre or taking active part in mutual aid society should be done in such a way so that the addressees of the invitation could feel that they are awaited by caring and understanding people. It is not always easy to express by means of words one's good will and true involvement. That is why it seems to us that our readers should get acquainted with a letter to a handicapped child's parents edited by parents mutual aid society in Freiburg in Germany.

Dear mother and father,

A few days, or weeks ago you learnt that your child is different. Perhaps your child has a kind of physical handicap. Perhaps there were some complications during the delivery and now you are afraid that your child will not develop properly or you already know that your child is permanently handicapped. It may also be that you are worried about their behaviour. However, in any of these cases the child is not as you imagined it to be. It is certainly a source of sorrow and sadness. We too are parents of children who are different. In the meantime they are from two to eight years old. We have been learning how to live with our children. But we can also be happy with them and of them. We would like to tell you how much our children have changed our lives.

Where should we start?

We could not decide for a long time whether we should write this letter to you at all. We do not know you nor do we know anything about your present life. We realise that there is no prescription on how to live with a handicapped child. However, we are writing to you in order to tell you how we were touched by this experience in many different ways. Of course our experiences cannot be passed on to your lives. You must find your own way of being with

your child and what is good for you. Some of the things we want to tell you may seem familiar and obvious to you. Some others, however, will sound quite strange. Maybe some of our ideas will help you see your situation in a different light and will give you enough courage to go on. Apart from this we would like to assure you that you are not alone - many parents feel the way you feel now.

The breakdown of our life.

Giving birth to a handicapped child may cause disappointment, sadness and anger. We also remember how difficult it was for us to learn that our child is handicapped. We lost our faith and hope. We experienced situations and saw pictures which we will never forget. Many things we planned and hoped for had to be given up. We were showered by uncountable problems and questions. We could not imagine our future life; we could not believe that our life can be normal again or we lasted in uncertainty. We wished everything was fine but somehow we supposed that something was wrong. We were overcome by an enormous fear. We did not want to accept the thought that our child could be handicapped. We picked up many activities thus trying to put the thought away. We did not wish such a child. We asked ourselves many questions: will we be able to live with such a child, will we manage to take proper care of the child, will it find its place in our family or will it destroy our life, will we ever go with our child to see our friends. We tried to hide away. At the same time our conscience accused us of rejecting our child.

What should we do to overcome the first shock?

Nearly none of us deserved to be told, in a special way, that our child „is different“. Since each of us parents is different and our children have different kinds of handicap, we all wished for an individual first aid. Some of the parents were not told exactly what this handicap of their child is neither did they know future perspectives. Some others wanted to get in touch with parents having the same problems and see the children with similar to their child's handicap. Still others needed someone to talk to, someone who could listen to them.

Advise of incompetent people may cause the pain.

It can be very difficult for us to go out with our child to see other people. It is very painful when a friend sees us with our child in a street and turns his head away or crosses the street.

Also the observant looks, shaking one's head or remarks on how to bring up a child such as „he needs a few slaps” make us lose our nerves.

Very often we have a feeling that we should excuse ourselves and defend against „good advice” of people who are not concerned with the problem, who think us to be too severe or too tolerant with the child, sometimes loving too much and sometimes too little. We are reproached that we neglect our handicapped child's brother and sisters. This kind of critic causes in us a feeling of grief. The child who needs most care is rejected right to it And we did experience that a normal child is able to ask for love itself, that in a way it develops itself. It can reach for things or take them from someone else's hand. With a handicapped child we have to practise it. We have to teach it life. Every next step of the development of the child is a consequence of countless exercises and is for us a source of happiness. That is why we have a more intensive approach to handicapped children.

It is so difficult to accept a natural approach.

The more we ourselves are uncertain and not firm in our attitude the more unwanted interruptions by other people in our private matters touch us. When we feel unwell the remarks and actions of other people hurt even more. When we feel better we can recognise uncertainty in the behaviour of others and we remember that we had thought and behaved as they do. Only then can we explain our situation and make the tense situation a little loose. Assuming such natural attitude comes easier to our children than to us. When Michael, who has only the thumb in his right hand, came for the first time to a kindergarten he was immediately surrounded by curious children who asked him why he did not have fingers. Michael's reply was: „I was born like that”. This was a good enough answer for the children and they started to play together. Soon the children noticed that Michael wants and is able to play despite the fact that he has not got all the fingers.

To be with us for the whole day is very often difficult. We not always know what he wants or if we made ourselves clear. In fact we do not have even a moment for rest; we have to be with our child for the whole time and take care of him. The things that seemed obvious so far had to be relinquished; Markus for example can neither bite nor chew but he should be given solid food. His mother must look to it, giving to this activity her strength and time. She cannot give up - she must endure it. Sometimes she has a nervous breakdown and she would not mind shaking her child in anger although she knows

that the things that happen are not the child's fault Anger is a sign of being overworked and is not directed against the child but against tense situations. We all know those moments when we are completely exhausted and would eagerly give up. Sometimes we need to look at our situation from a distance and have some time for ourselves. If we are feeling better we can easier overcome the difficulties of our daily routines with our child.

We must find our own way.

As handicapped children' parents we are dependent on an expert help. They tell us what to do. In the first period when were uncertain about what to do we acted exactly in accordance with their advice and suggestions thus very often acting against our own feelings. In the meantime we already know that it is us who know our child better and we have the right to either accept or reject suggested therapy. Sometimes we have to protect our child and ourselves against too many exercises. Sometimes, on the other hand, it is necessary to find a proper kind of therapy and fight for its approval. No matter what we decide - eventually, we are responsible for our child although the decision may be very hard. We may choose the therapy which is rejected by our child. One of the mothers in our group asked a question in reference to an exercise: „Is this ill-treatment of my child or the only way of helping him? How can I tell?" We need to take decisions not only concerning our child but also our family again and again. What amount of therapy can the family endure? Where is the limit? One of the mother's answers was: „You need a lot of time, strong nerves and five times more work than usual. Summing up everything I have to do for my child I counted more than 250 various kinds of activities and appointments. Only for one child in a three children family". Each of us must make their own choices, must have their own responsibility and do what is good to them and possible in practice. A contact with people having similar problems can make it easier to make such decisions. In our group we share our knowledge.

Gradually we learn what kind of person our child is.

The information 'your child is different' meant solely the knowledge about the handicap of our child. We concentrated on the illness and had no objective view of our child. That is why only very slowly could we learn that behind the handicap there is a personality of a little man. Michael's mother could not then foresee that her son will infect her with his gaiety and that she herself will regain a happy spirit. Julia's father never expected that he would ever

laugh at his daughter's jokes. Aneta's mother is surprised that despite her daughter's handicap she may be proud of the child. Andreas' mother says today: „I would never replace him with a healthy child”.

The way of learning our child behind his handicap has no end. Every day you have to start anew. Sometimes there comes a very hard time when the handicap seems to be very strong and immense as if shutting out the view of our child. It usually happens when we see a normal child of the same age and suddenly we realise how different our child would be. But there is also a better time when we have a closer contact with our child and we can accept him as he is. However, in any case, the way of learning is not easy. You always encounter new disappointments and worries. Only now do we know that it is important to admit sorrows and worries in our lives.

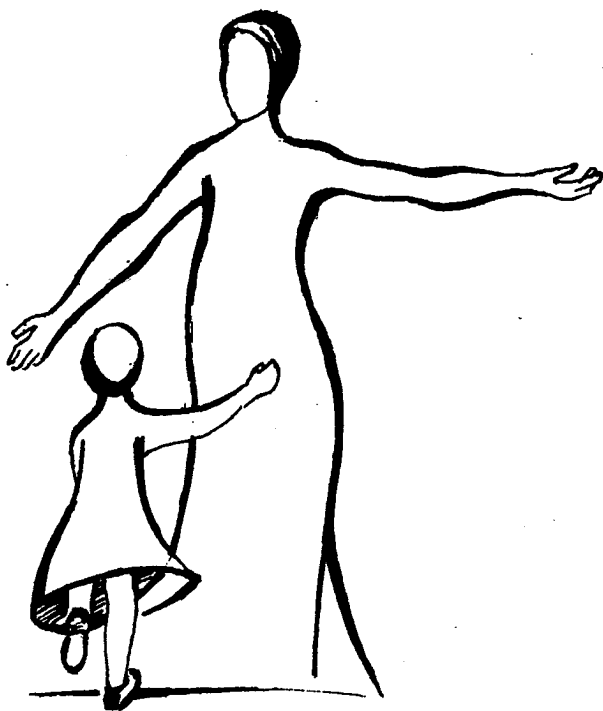
Contact with our child changes a lot in us.

Comparing our children with normal children is always to disadvantage of the first ones since in their case we cannot count on achieving further normal steps of development. But if we compare our child with himself, which means according to measure proper for him, we can see changes. Unexpected steps of development are then a small miracle. That is why we have learnt to notice and acknowledge those little changes which for others remain unnoticeable and for us are a source of happiness. Claudia's father is happy that his question: „Are you happy” is understood by his daughter who in contact with the environment shows great delicacy - she even strokes grass. Hanna's mother fell into despair when her eight - month - daughter stayed in her bed motionless. A three month therapy did not bring any effect. One day when the mother lost all hope during the therapy her daughter started to smile. Then the mother cried of happiness, not of sorrow.

Our handicapped child engenders in us profound feelings which we have not known so far. It is impossible to describe them. Some parents say about 'a sort of softness of feelings' in themselves some others about an unusual richness of their heart of hearts. One of the mothers experiences her child as a 'rising sun'. Another says that only behaviour of her child called her attention to her own feelings. One of the fathers realised that he could not live as he used to live so far and that it was only thanks to his daughter that he changed. By being with our child we experience that we cannot decide about our life nor plan the future in a sure and unequivocal way. This helps us live in the present more consciously. We also try to demand less from ourselves.

We learnt to admit that we are not able to do everything. By accepting our child with all his fragility we could accept our own weakness. Now it is easier for us to see our child as he really is. Only if we stop constant efforts to change him can we say: „You do not exist to be as I want you to be”.

Parents from Germany



PARENT'S ADVICE

- If it turns out that your child is stricken with underdevelopment you must not fall into despair or lose your head. It is not easy but you must do everything not to panic. You must both help one another not to lose your heart.
- In no circumstances should you look for someone to blame, especially your spouse or his/her family.
- You must not ask yourself the question: „Why did it happen to me not to X?“. When you have such a temptation you better ask: „Why should it happen to X not to us?“.
- At the beginning you may protest against God. How could a Merciful God let something like this happen? Protest in such a case may be a natural impulse which you should accept with composure. In the course of time the things will be back to normal.
- From the very beginning you should consult an expert doctor. Nowadays, medicine has made a great progress in the field of underdevelopment. In the case of your child you must not fail your duties.
- Rehabilitation of your child is very important, both in case of underdevelopment and mental deficiency, or when the child is stricken by both at the same time. Physical rehabilitation is also very important in the case of mental deficiency. Permanent and systematic medical help is a must.
- You must work on attaining a conviction that your child, in his handicap, is a human being in the full sense of the word. He was created by God and perhaps God has chosen you to be his parents because he knew that you could give him possibility of living and developing in love and harmony.
- Do not put your child in a home for disabled even if somebody advises you so. A child must have a family.
- ~~Make sure that your child does not only stay at home. Find communities and~~ organisations of families like yours, for example a community of „Faith and Light“. It is good to come into contact and to co-operate with several communities. You will find out how much good there is in the world - also in your circle. Getting into touch with a community will help you send your child on a camp (also in the case of deep handicap) thus easing you some of your work. Caritas runs community centres for children of various levels of handi-

cap. While your child spends several hours a day there you can rest not only physically but also mentally.

- Make sure that from time to time you rest from the duties of looking after your child. It is necessary for your health.

- If your handicapped child has brothers or sisters - prepare them for a new situation. You should realise that the brothers and sisters may be at first ashamed of their impaired brother or sister. This, in the course of time, will change into a special kind of love and care. You should explain to your children that you do not treat the impaired child in a special way because you love him/her more but because he/she needs such special care.

- Tell your neighbours' children what the handicap of your child is and try to encourage them to show special help and friendship to your child.

- Do not take impolite interest in your child to heart (importunate looks of your neighbours or passers-by). You may then ask: „Would you like to help?“. We find that the attitude of young people towards the handicapped is much more appropriate than the attitude of older people. The fact that in all kinds of communities it is the young people who help the handicapped confirms our conviction.

- Try to walk a lot with your child - it is not only a good exercise but also a source of impressions and stimuli.

- If there is a possibility that a guardian from the community centre can take care of your child for some time go away from your child's view. Let the guardian take care of your child himself. It is very often the case that the child is more obedient to a strange person than to somebody from the family.

- A handicapped child should take active part in religious life. Take him/her to the church, tell them about God, let them take part in the Holy Mass. On certain days there are special Masses for the handicapped.

- Being a member of a community gives to you and your child possibility of taking part in various parties and meetings held on the occasion of different festivals.

- Try not to think about the future too much, do not worry about what happens after your death. You must do everything to safeguard the future of your child but you must not let the worries overwhelm you. There are being started new initiatives which are to ensure help for the handicapped after their parents' death. Remember that you are not alone in problem.

- When you have already accepted your situation you will find out how much it adds to your spiritual development. This handicapped child of yours enriches you and lavishes goods on you. You will understand that were it not for him/her you would be totally different people.

Kazimierz Traciewicz



I AM GOING TO BE A MOTHER

MARCIN

It's 1970. In few weeks time I will be a mother. I am 29 and this is the first pregnancy without miscarriage. For the father of our child it is the third birth: He has two healthy children from his first marriage. I am a little bit nervous, as always when you don't know the future. The doctor says everything is fine and we are waiting. 5th January 1971. I'm feeling a pain in the small of the back and I stain. My husband-doctor says: „The birth has started”. The pain is too small. I'm going to a clinic. The doctor doesn't examine me but says: „It will be a miracle if you give birth in 24 hours”. He is wrong. I start giving birth right after I leave the clinic. I am wet and I feel that I have everything down in my perineum. An ambulance takes me to the ward. A midwife doesn't examine me but shouts: „Stand up and walk!” In a moment it turns out that the navel-string falls out. In a terrible hurry I give birth through caesarean operation. At the time of losing conscience I hear the voice of the surgeon: „Hurry up! the pulse rate of the child is fading down And again I hear the voice of the operating doctor: „It's a boy. Weight...they give parameters. His left foot is distorted, his head is flattened and besides - congratulations. Everything will come to normal.”

Marcin is growing up. There grows a fear in me that there is something wrong with his eyes. I consult it with a paediatrist. „At the age of eight months we don't treat eyes diseases” he answers. I have a feeling that I don't have any contact with my child. I share my feelings with my husband. He ignores it. He forbids me to go from one doctor to another. In the course of days and weeks I'm starting to be convinced that Marcin is developing in a normal way. In time there come and go the usual illnesses of the children's age. I don't go to doctors as my husband suggested. He is a doctor, too. Our financial conditions become worse. We must gain some money for the flat and my husband decides to go to Algeria.

The first medical signal

New Year's Eve 1974. Marcin has ambilateral pneumonia. We send for a paediatrician from neighbourhood. Apart from stating ambilateral pneumonia the doctor makes another diagnosis: „There is something wrong. You

must immediately consult a neuropsychiatrist." He helps make an appointment. The diagnosis is: cerebral paralysis, epilepsy. I am given a note to the hospital, a special ward. The diagnosis is confirmed. From a woman ward head I hear the words of good cheer: „There is not even a piece of healthy brain." After I left the ward - thank God the driver was level-headed... To my letters to Algeria my husband answers: „Take the child from the ward, come to Algeria, don't panic..."

I leave for Algeria obediently equipped with medicines and fears. When we land on the African continent Marcin is taken on the stretcher, unconscious.

Gehenna of Algeria

There are no promised French doctors. According to my husband there is no illness! But there is a very hard climate of Africa which is not propitious to Marcin. Fortunately, there is a Polish psychiatrist who is ready to help us. We treated Marcin ourselves holding it back from my husband. Psychiatrist's wife sends medicine from Poland. Marcin's state becomes worse and worse: he cannot hold stool or urine, he has attacks of petite mal epilepsy changing into a state of epilepsy. He is restless and uproarious - he suffers.

My husband surgeon who works very hard in a badly organised hospital in Sefifa cannot bear the situation. He tries to stop the illness by slaps and throwing away of the medicine. I myself already know that our marriage is over. We come back to Poland against the will of Marcin's father.

Back in the country

Marcin's state is very hard after our arrival. Immediately I take him to hospital, this time it is a special clinic for children and youth. At the same time I am given a note to the institute of professor Popielarska in Warsaw. Then being still an assistant professor she welcomes us saying: „Who would be so stupid to take an ill child to Algeria?" Another diagnosis: „Encephalopatia with epilepsy attacks, with mental handicap and psychomotor agitation." From then on in our life there will be more aggression and in further diagnosis the term 'psychomotor agitation'.

Marcin screams, throws objects, throws himself in the puddles in the street. The passers-by look down on us and comment: „What a aggravating molly-coddle". We run from one specialist to another. We bring gifts and our suffe-

ring. We change doctors and clinics. We are waiting for hope. there are periods of remission - the illness fades down but they are shorter and shorter while the periods of hospitalisation longer and longer.

Friendly people tell us about a special kindergarten. We try. I have to go to work. My son is a difficult and absorbing pre-school child. We try to attend regularly. The nursery school teachers do their best. Marcin begins to articulate simple sentences, his drawings are scrawls. We need to rehabilitate motor activity. He is distempered.- Marcin treads spastically and he loses balance on an even ground. He has manual problems, too: he gets hold of things like a monkey-baby. We begin rehabilitation at home. We - does not mean me and my husband anymore - we parted as friends. I am convinced that he was a great surgeon but he should have never been a husband. He thought of me as of a mother only, not as of wife. In my life there appears a man who together with me decides to take up the burden of taking care of Marcin. He stays with us for better and for worse. More for worse, however. One has to carry the burden patiently. We have to teach Marcin how to dress, how to button his shirts and do up the shoe laces. This lasted for three years. Everyday in the form of a game. Marcin and Jacek were buttoning and unbuttoning, doing up and undoing, even for a few hours a day. They were walking and falling down on hills and stones in order to prevent Marcin's falls on an even ground, in the streets. I tried to come to terms with myself, to accept the situation, to leave behind the period of rejecting the reality. It was very hard. The word „Kobierzyn”* itself made me feel sick, caused headache and long lasting depression. I did not know then that there would come a much worse time.

School

Marcin was growing up. He found himself in a school of life. The attacks of aggression grew stronger. This state was called 'temporal lobe epilepsy'. I changed my profession and the place of work. Marcin does not want to go to school more and more often. The school is a very good rehabilitation place but the illness is stronger. Our everyday life becomes disorganised. Marcin begins to be somatically ill.

* Kobierzyn - a village near Krakow with Psychiatric Hospital

In the house the windows are broken, the walls are spotted with some liquids stains. On our heads there are more and more bruises. Around us there are less and less friends. In my editorial office my colleagues were sympathetic and worked for me. The doctors kept on changing medicines and advised to put Marcin in a social care centre. I, on the other hand, kept on changing doctors and learnt how to escape on time and, by means of various tricks, how to gain time. When Marcin had 'bad time' I tried to amuse him. He had a specific sense of humour. The most funny was when a 'catastrophe' happened - when something got broken or when somebody fell down and it was best if this somebody was I. The illness was stronger. A warm-hearted doctor said: „He will kill you”.

There came time of saying good-bye to the school of life - prematurely. The verdict was: „dangerous to the environment”. I try to change the environment and try a pedagogical manoeuvre for healthy children: I try the school for normal children. Unfortunately, it worked only for three months. Our house seems to function. We seat paralysed with aggression. New hospitalisations, group psychotherapy, individual therapy, family therapy. At home again. There is no school of life anymore.

Individual tuition

I am an editorial office worker, cook, cleaner, teacher, therapist and scape-grace at the same time. Our living conditions become worse. We cannot manage with our daily life. We also do not ask for any help from the social welfare. We grew obstinate - it is our problem and nobody else's. From a one-room flat we move to an old and ruined small house. With our own hands we try to bring it to life again thinking that for Marcin there will be more space, a garden - it will be better. The time is running. The teachers who cannot bear the feeling of danger change. Besides, Marcin's condition does not allow to accomplish the teaching programme. The teachers play the role of guardians only. I went through several situations when, miraculously, I avoided a deep physical handicap, but there were also a few such cases when miracles did not happen. There were ambulances, plaster of Paris cast, hospital. There were cases when Marcin beat up our visitors. The attacks of grand mal appeared. The leading doctor keeps on giving us notes to social care centre and I keep on putting them in the drawer. In this battle of survival there are good and even happy periods Marcin is calmed down and takes part in family cele-

brations, spends holidays with us and the community of „Faith and Light”. Beautiful girls and young seminarists visit our house - wonderful youth who take Marcin on excursions and camps. They are nearly of the same age as Marcin. Maybe this will help. There is hope again but my son brings it to naught. There begins another relapse into illness - it is dangerous and we have to leave the camp.

In the starting point

My obsessive reluctance to put Marcin in a centre is suppressed by a tragic event. A day like many other days. Marcin has a headache and stomach-ache alternately. I pick up the receiver and hear an anxious voice of my husband. I do not manage to answer. The first blows fall on my head, I drop down the receiver and fall down myself. I do not manage to escape. the girl from the neighbourhood who was in the house runs away latching the door - I have no chance to run away. Marcin, a 19-year-old, 196 centimetres high, hits with his hands and kicks. I lose conscience. Railway workers who work nearby rush in the last moment.

In a psychiatric clinic, Marcin is awaiting an allocation in a social care centre. I am still in plaster. My bruised head still aches and my heart aches the most. I feel as if I betrayed him.

Another home

It is a late August day of 1989. The beauty of the region attempts to reward what will happen in a moment. Marcin stays in social care centre in Pawlikowice. Without me...

The living conditions are rather poor there. I try to level the difference as much as I can. There is lack of professional staff. But there is a greater chance of making Marcin more active in social life as well as making him more self-sufficient. The chances are that nearly two hundred people community, staff included, will manage before the consequences of temporal lobe epilepsy appear. There is a new director of the place, which gives hope for some changes. And there is me - always present in Marcin's life. I try to soften the effects of changes and bring into this strange for him world a little bit of family life. I disagree with the situation; I miss Marcin, I feel guilty. First attack of temporal lobe epilepsy takes place in less than three months after

Marcin's arrival in Pawlikowice. Another hospitalisation - this time at the ward for adults in Kobierzyn. The clinic renounces a patient from social care centre. Marcin is treated, and learns life, together with the patients of alcohol disease and those of characteropathy. Because I cannot agree with this fact, I try to intercede with the clinic for Marcin, who three months earlier left the clinic having made some progress towards a cure and was its patient of long standing. I did not achieve my purpose - those from social care centre should know their place. Ill-will of the doctor towards Marcin shows itself in his amazement: „He is too neat as for somebody from psychiatric hospital”. I decide to astound those who divide patients according to some categories: I choose what Marcin will wear, I wash his clothes. I take my son to various doctors specialists and to diagnostic investigations. I get better medicines from abroad, supply Marcin's diet with meat, fruits and dainties. I take my son to family celebrations, longer lasting passes. I take care that his names-day and birthday is celebrated, that he has Children's day; I take him on holidays.

Unfortunately, the illness unsettles our stabilised family life. It looks differently this time but it is as strong as it was. I receive a phone call from Pawlikowice: Marcin cut his veins. In a hurry I get ready for a meeting. The cases of self aggression haven't occured so far. But there is another phone call. Marcin, during the attack of temporal lobe epilepsy, hit a chief nurse who was not prepared for the patient's reaction. Longer hospitalisation and Marcin is not allowed to return to Pawlikowice. The staff threaten that they will quit their jobs and they are backed up by an opinion of a psychiatrist. They do not want Marcin in the institution. We must change the house. The director from Pawlikowice helps us. Marcin goes to Czerna. A small coeducational place with people of various ages. Nice family atmosphere. Marcin is welcomed with hospitality but it turns out that the place is only a short stop before a further journey. With his illness he cannot stay here for longer.

Lyszkowice

August again. In the region of Proszowice farmers reap the last harvest. Being richer by the experience of the last two years I can see more and I compare. In the centre there are mostly older mentally ill patients at the moment of the remission of their illness. There are no young people. The chief nurse of the men ward has a good heart and ambition to be better. This brings results.

Marcin, as the youngest, is paid regard to. He is accepted and liked by people there and he feels it. There comes the time of favourable circumstances for the social welfare. There are new plans worked out in co-operation with foreign centres. There begins a period of adjusting the centres to particular illnesses. A new director is in charge of Lyszkowice now. Under his administration the centre begins to stand out in the region of Krakow: variety of activities, a modern rehabilitation scheme, modernised buildings and many interesting plans for the future. Marcin's psyche calms down and his soma has a repercussion. He is constantly unwell. We do specialised diagnostic investigations, usually in private consulting rooms. Public health service is dying out. Long lines of those waiting for help are for the healthy people. Because of his illness, Marcin is not able to wait. The syndrome of vicious circle begins to work. Somatic illness speeds up the return of the psychic illness. There are first conflicts. Finally, there comes the worst. During the attack of temporal lobe epilepsy Marcin bit his guardian..

During the next two years Marcin was hospitalised five times, every next stay being longer from the previous one. In the centre the atmosphere of fear and aversion grows. The director of the house treats Marcin's case with understanding and professionalism. She prepares an individual plan of his therapy. She does not avoid difficult cases - she is an expert and she is good-hearted. The case is worse with the staff. It is difficult to change their turn of mind despite the courses of instruction organised by the director. We will have to wait for the change of customs and mentality. In the mean time the patients are ordered. The guardian in the rank of ward attendant appears to Marcin as a 'sergeant in skirt'. He heard from his colleagues that it is not a military ward. He repeats in a way of echolalia and is accused of conscious beating. The aversion of the staff is so big that Marcin feels it. Despite the director's good will, Marcin does not want to stay in Lyszkowice.

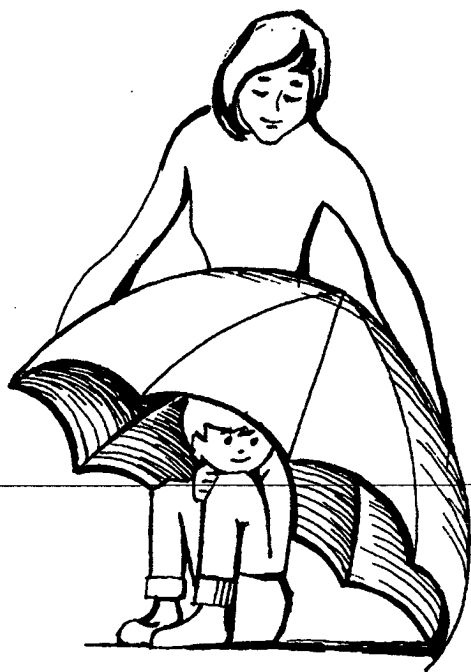
On the way

We set up for a change of places again. This time to Heburtowice. Since two years it has been said to be a model place: modern, with professional staff - a clinic psychiatrist, a psychologist and a doctor of pedagogy. Nicely situated house, single and double rooms, fashionably equipped. Workshops of occupational therapy nearby. Marcin is to attend the workshop in the future. I am

going to decorate his room myself. Then a thought runs through my head: "It is too beautiful to be true". It was thought in a wrong moment.

9 October 1996. After a month and a half of his stay in the new house Marcin goes to a neuropsychiatrist hospital. He threw a glass in the direction of a chief nurse who could not believe that Marcin had a headache. A group of specialists becomes active. I am on the side of the staff. They must be protected against an arduous patient. They will do everything to prevent Marcin from coming back to Harbutowice. They suggest that I should leave Marcin in Kobierzyn permanently. Fortunately, there is neither lawful nor medical possibility. Fortunately, there is me - a lawful protectress and I will do my best not to put Marcin in Kobierzyn. What a shame professor Kempieński is not with us any longer. He would find „an escape from life” for my son.

Mother



WHAT IS ESSENTIAL FOR A DISABLED CHILD

Mykola Swarnyk, parent, Lviv, Ukraine

Whenever I speak with parents, who have just learned of their child's disability, I begin to feel anxious and somewhat helpless, remembering the quite nightmare which ensued when I too received such unwelcome news. The shattered hopes of the future I had imagined for my son, the feeling that all life plans had been abruptly dashed, and the fevered search for a miraculous recovery. The vicious circle of alternately blaming myself and blaming doctors. All of this brings out a great sadness in me, along with compassion for the parents - and for myself.

When this booklet finds its way into your hands, it may be a month, or six months, or a year after that tragic moment. Remember - the worst has already happened. If you are repetitively reliving the shock of when the verdict was first delivered to you, it is time to somehow stop this. Perhaps it would be worth analyzing and reflecting on this „defeat”. Work, career aspirations, relative freedom... what in actual fact did we lose, and what did we manage to retain? Perhaps earlier we were able to be our own masters, and now we feel totally tied down? Maybe we had set an important goal, and now it has become unattainable, a distant memory.

More than likely, all of this is true and we must come to terms with it. All in all we have not disowned our child, we have not abandoned him or her, we have not been defeated by the hardships with this unique parenthood has presented. We have not throw up our hands and are doing our best to be a good mother or father. We are striving to give our child everything that is necessary for it to reach its potential. Even the smallest thing which our child accomplishes becomes our reward. We give our child all our love and we sense our child's loving faith in us. I think that perhaps some of us for the first time found a real goal and true meaning in our lives, and have come to understand the real worth of love and freedom, goodness and honesty, generosity and wisdom.

About feelings

Each of us has the right to show our feelings, including anger, frustration and

hurt. It is no secret that a disabled child is often a source of frustration which brings out both feelings of guilt, and of being wronged by the world. Sometimes with this comes the laying of blame on a family member. However, think about how this affects those around us - the husband or wife or mother or mother-in-law who is being made to take the brunt of our feelings of guilt. Often we exercise a huge tolerance for the child itself, using that as a form of compensation for placing unrealistic demands on other members of the family, such as an older child. It is here that we must be extremely careful, even though it is hard to imagine that a healthy child could be jealous of a disabled one. But if you are delivering only sweets, toys and kisses to the weakest family member and reserving the dustpan, mop and dirty dishes for the others, this will lead to a jealousy expressed through covert or outright rebellion.

This also holds true for adults when they are neglected. An adult is, after all in many ways the same as a child - only bigger. I think it is best for children and adults if love is given wisely to all. For love is such a wondrous thing, because when it is divided it does not become smaller but multiplies in volume. The father, eldest child or grandmother not excluded from the tired mother's attention, but allowed to be part of the family, will help with the disabled child and share in the love of the family.

My most deeply-held belief is that what the child needs most is love and kindness. A warm meal, clean underwear, vitamins and fresh oranges will of course fulfill some of the child's physical needs, but none can substitute for love. In the same way no institution, not even the very best, can substitute for the child's home.

Learn to show your love. Love is primarily demonstrated through communication. A baby does not understand words but it does understand the praise and encouragement it hears in the intonation of your voice, just as it understands handling which is tender or rough. In turn the child's reaction, even if at first glance it appears unresponsive, tells you if the massage was good or bad, if the clothing fits, if the food is tasty. Remember that sometimes a child will have difficulty differentiating and expressing its feelings due to a decrease in its ability to feel sensation, tranquilizing medication or spastic muscles. There is a great likelihood that it will be necessary for you to remain extra sensitive to the child's reaction not only during the first year, but until she or he is three or even seven-years-old. Such „one-way” communication is extremely important for the child. It is helpful to continuously talk to the child, use the child's name, describe what you are doing, tell stories and rhymes, and

sing songs, even though sometimes it appears that the child is not responding at all. Carry on your monologue, and sooner or later it will become a dialogue. I know one mother who only realized in her child's twelfth year that the child had been listening to her and understanding her all along, but did not have the physical ability to let her know that. What immeasurable joy it brings to a mother and child learn after twelve years to understand one another because the mother did not give up and was always searching for some way to communicate.

About „building the fortress”

The question, „Is your child worthy of love?”, may be a strange one. Since you give love to your child, then perhaps there are others who can do so as well. Even a brief glance at our immediate surroundings will help you discover kind and sympathetic people among close and distant family members, and among friends and acquaintances, who will gladly help you with the care of your child. Many people have probably offered their help which you have inadvertently turned down, or perhaps they want to help but do not know how to tell you for fear of offending you. Find these people and include them in your circle of relations, because this above all is essential for your child. You will run yourself into the ground if you attempt to do everything yourself and don't let anyone come within a mile of you. It is simply not true that people are hostile or rejecting or are laughing at your child, often parents who hold such an impression feel embarrassed that their child is „not as it should be”.

Next, seek out other parents of disabled children because you will not feel a need to be embarrassed when you are with them. Sincere and open discussion will help to bring you out of a position of defensiveness and help you to see the world with new eyes. You will receive a lot of information (about which you should be selective). A parents' organization can be of great help you from aiding you to find an appropriate wheelchair to directing you to the a rehabilitation program. Some of these organizations offer their own rehabilitation services which are often better than public centers. All in all, having contact with other parents who share the same problems will give you a new lease on life. In turn, you will gain new strength when you help someone else. I know many parents whose lives were given new purpose and meaning, thanks to their disabled child.

You can also turn to youth organizations in your area. Young people today

are much better than we think. They do not have old „hang-ups”, have a lot of energy and will gladly help when they see positive results emerging from their efforts. For example, young men's and women's Christian organizations and scout groups run camps, hold social gatherings and celebrations for disabled children. Often these young people can stay with your child when you have obligations outside the home or take him for an outing when you have housework. They would give you an opportunity to go out for coffee, to a concert or to visit friends. Your helpers will gladly understand you.

As hard as it may be for you to accept your new reality, it is necessary to remain open to the world around you, and to maintain normal contact with those around you. The best results will occur when your child can have as much contact as possible, both with disabled and „healthy” children, teens and adults. No matter how disabled the child, you should give it the same opportunities as other children. Moreover, if ours' is to become a better world, parents should crusade for the integration of disabled children in all areas of society...

I don't have patience for parents who continuously cry and complain about their tragedy. Your child deserves the love of family and friends, deserves to experience optimism and the joys of being with others, and deserves - win or loose - to have the self-confidence to try something new. Sometimes a mother will spend hours on the phone talking about how difficult her life is, with her child sitting in the corner and listening. Such a mother is a walking example of her own tragedy. She is so taken by her role of the mourner, that she does not see and does not want to see any good around her. Later, the child itself will learn only to cry and complain, rather than learn to delight in life, overcome tragedy and laugh at misfortune.

About trust and distrust

You were most fortunate if, at first, you had an opportunity to talk to a knowledgeable doctor. The vast majority of parents feel greatly offended by doctors, nurses and therapist, who determined that their child had no potential. Worst still they advised them to give up the child for „your own good” and, even, for the „good of the child!”. We know the Ukrainian experience to be that every single (!) family with the severely disabled child was advised by the doctor or nurse at any opportunity and often more than once to give up their child to an institution. In this instance, my best advice is to take such an

advice with reserve. Generally people believe in and want to hear positive and good things. There are many examples of parents who did not heed the verdict of the doctors and along with their child were able to claim victory in the face of the frightening prognosis.

On the other hand there are many incidents when the doctor, after the initial assessment of the child missed important and obvious pathology or gave false assurances, such as, „Don't worry, he'll grow out of it". Therefore, don't ever believe your child is „hopeless" or that the circumstances will eventually go away. You should have the child thoroughly assessed and then realistically reassess the situation yourself.

The best course of action for the child comes from a combination of hard facts and the dictates of the mother's heart. Once you have the diagnosis, then determine objectively what your child needs and then put yourself in your child's place to determine what he or she would want given the opportunity to take action on it's own behalf. Take all the findings and opinions and weigh them against the advice of specialists and so called specialists. Evaluate the nature of the love in your heart and the information you have gathered and heard. If you sincerely want your child to live surrounded in love and truth, you will in time learn to heed the good counsel and ignore the bad.

About „wasted time"

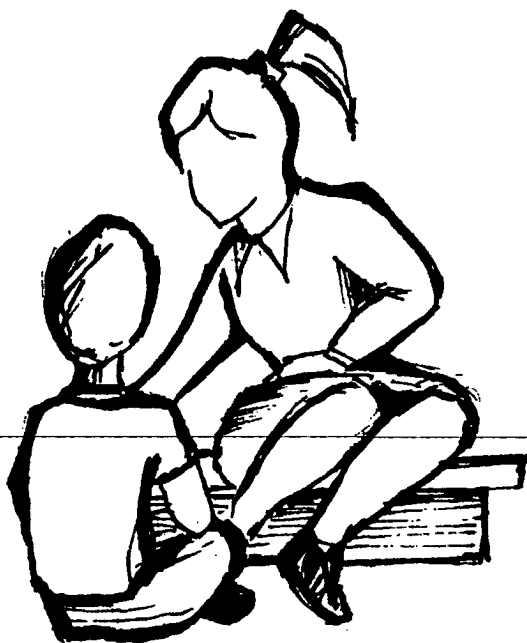
Often one hears that it is very important to take advantage of the first few months following the diagnosis, because it is in this period that rehabilitation delivers the best results. And it is true that the nervous system is most receptive in the formative stages of life. Holding with this theory, many parents virtually drive themselves and their child into the ground in the passionate search for the most effective treatment methods. Frequently, the end result of this is immense frustration if the child does not „justify" spend energy and invested money for treatment. Later they say, „We tried everything we could and it didn't help". Or they say, „They told us to try this or that but we couldn't decide whether to do it - and now all is lost". But with severe organic deficits the child cannot be totally cured or it will develop at a slower pace than children of the same age. Every new year of your child's development demands perseverance and innovation, and new capabilities on your part. Every stage of growth demands specific methods of treatment. The reality is that nothing works in the short term and you have to count on the long haul. You must not torture yourself with missed opportunities. Because every day

may bring a new problem or a pleasant surprise. You must be ready for one or the other. Many parents told me about revolutionary and amazing achievements, which occurred for the first time at 8 and even 14 years of age. Your continuous effort with your child can bring results in the most unexpected areas at the most unexpected times.

Once, while riding on a bus, I heard this conversation, „I so believed in democracy and were is it now? They've stolen everything. I'll never believe in anyone to the end of my days". To this an old man remarked, „One or the other - either your faith was misplaced or it was to weak".

I think the development of a disabled child is the same as with democracy - you must always believe, no matter what, and strive every single day.

To conclude I would like once more to return to that feeling of disappointment which arises in our thoughts from time to time. How can we come to terms with the fact that our child is truly not like the other children. When the children of your friends are going to school and yours can't even walk. Or when it can walk but cannot learn to write, ride a bicycle, or play the piano.



Perhaps your child has difficulty maintaining attention or communicating. When you're very tired and feeling there is no way out, perhaps the thought enters your head that you were cheated and that you were given a third grade item or one totally worth nothing. Or sometimes worse and one feels imprisoned or severely punished, 24 hours a day tied to a disabled child, to endless diapers and laundry, cooking cereal, wandering from one hospital to another with no possibility for change or improvement.

But the day or month passes, and once again you feel the life of the child is a priceless gift. We didn't choose to take or reject this gift - we were chosen by Him for it. It's left to us, how we use them. Again we see in our child its uniqueness. We see in our child its purpose - the purpose to be our child, purely to bring out and receive our love.

Good luck to you as you travel on this road.

A MOTHER'S PERSPECTIVE

Cathy Ficker Terrill

„We have long recognised that people with disabilities are some of our nation's greatest untapped resources. We believe that all persons with disabilities must be fully integrated into mainstream society, so they can live fulfilling and rewarding lives”.

Bill Clinton, 1992

Choosing to have a child is a gift. Having a child with a disability is a gift of joy. At first you feel as though you have experienced a loss, but soon you discover that this unique child has abilities and talents that will surprise you. Children with disabilities used to be associated with life in an institution and segregated from the rest of the community. Perceptions of people with disabilities have changed rapidly. Today children with disabilities are attending regular schools with specialised support. Adults with disabilities are living in small supported homes in the community, working at jobs and participating in community recreation activities.

Early Intervention is needed to support families. These services prevent or reduce the negative effects of disabilities in early development. Early Intervention promotes the optimal development of the child and prevents the emergence of more severe and costly problems later on. Early Intervention services include family training, home visit, respite or relief care, speech therapy, physical therapy and assistive devices. Early Intervention should be a service not a building. Early Intervention services should serve children and their families in natural settings where infants and toddlers typically are found, such as the family home, day care, playgrounds, churches and other community places. The trend is for the services to come to the child rather than requiring the family to take child to services. Services should be flexible in meeting the needs of the families with different lifestyles, cultures, schedules and priorities.

The best Early Intervention programmes recognise the family as the major caregiver for the child and include the parents as active partners in planning for the child's needs. Families are trained to use therapy techniques at home

everyday. The family has the knowledge and the information needed by professionals to determine how best to meet its child's needs.

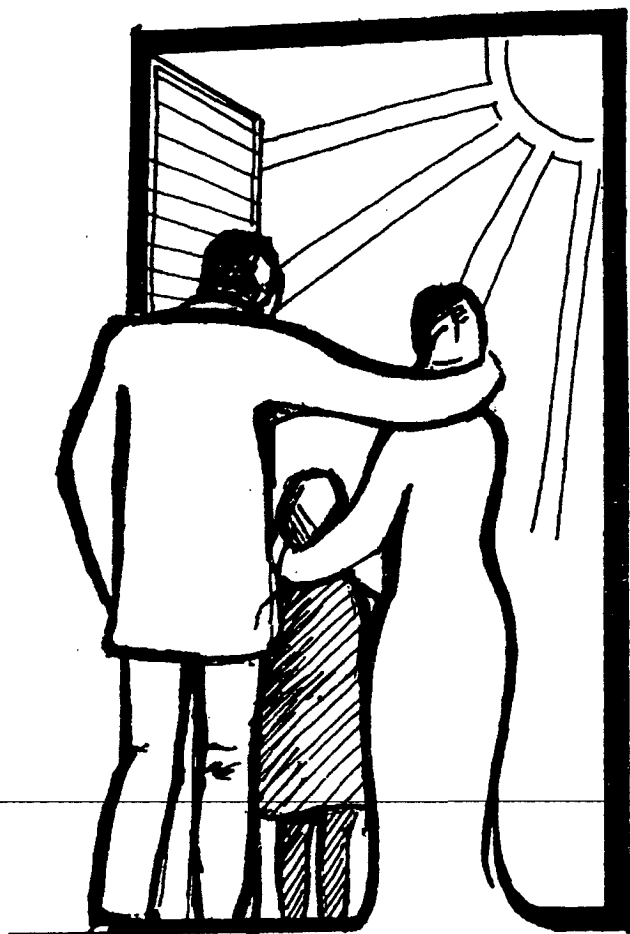
As you set up agencies to provide services to children with disabilities and their families, it is important to clearly define the mission of your organisation. Parents must be involved in setting up these organisations. All of your work must be clarified with a set of values or principles to guide your work. I would suggest that you consider the following values to guide your work:

- Children should grow up in a home with their family, rather than at an institution
- Children should attend regular school classes with supports rather than be isolated in segregated programs
- All people have abilities
- Communities should be accessible for people with disabilities as they are for people without disabilities.
- We all share the same freedoms, privileges and civil rights.
- Families should be recognised as an important resource and they should be supported.
- People have a right and responsibility to make choices in their lives.
- Children with disabilities benefit most from training in typical settings where they can learn independent living and work skills that will enable them to live and work in the community

Families that have a child with a developmental disability cope with emotional stress, time, demands and financial cost. Government needs to create family support programs to help parents locate resources they need. Direct assistance to families is more cost effective than institutional placement and more beneficial to the child and family.

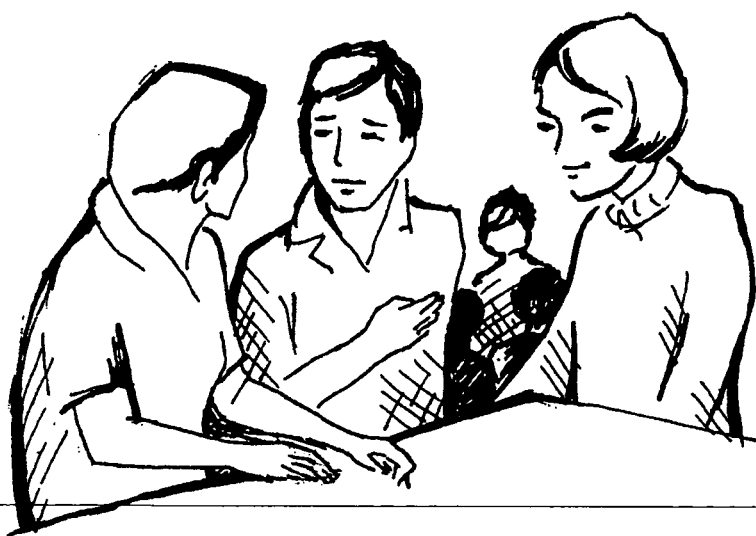
Parents need to meet together to share ideas and affect change. All children should have the right to an education so they can have the tools they need to live, work and play in their communities. Every family knows someone with a disability. As influential community members, join your fight for better services and a better life for your child. By working together you will make a difference.

By working together you will learn that all children have meaning and purpose. It is for us to determine how to best support all children so they can learn and grow. We will all mature at a different pace, but we all have a talent to bring to the world.



Part II

PROFESSIONALS TO PARENTS



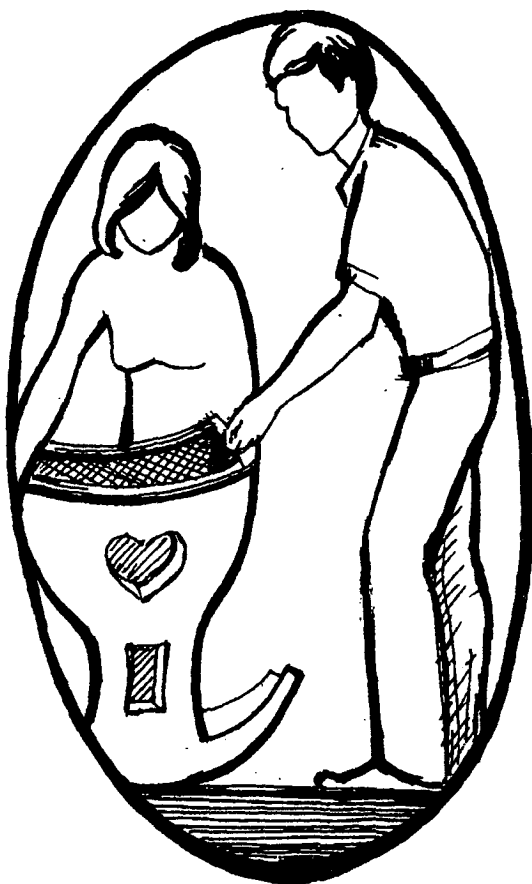
WHEN OUR CHILD IS BORN

The moment of the first encounter of parents with a child just after birth is one of the most wonderful in our life. All parents wait for this joyful moment with great impatience, but at the same time with great curiosity: What is it going to be like? How is it going to change our life? How are we going to be together?

Each of us awaiting this important event nurses his/her own dreams and wishes that they will all come true. When the reality differs from the expectation, we are enveloped by all kinds of negative feelings which make it even more difficult to cope with finding ourselves in a new situation.

It occurs both in simple and more complicated events in our life. Each of us remembers the emotions and feelings experienced in a situation when a long-awaited and treasured guest did not arrive, while the preparations for his reception took a lot of time. At the beginning there is anxiety, and later fear replaces our fading hopes, also anger, frustration, and ultimately a feeling of regret and sorrow. Gradually, after a few hours or days we try to get back to a normal way of living. The process of dealing with such serious events as the discovery of an incurable disease or the sudden loss of somebody close follows a similar course. It is the same when a child with developmental retardation is born.

Each family, especially the mother, experiences a shock, and an emotional crisis with strong fluctuation of feeling from hope to deep sorrow and despair. After this they try to reorganize their life and family. This process of construing a different vision of their lives can take a shorter or longer time, from one up to three years. One has to go through it, and the shorter it lasts, the better for the mutual contact between the child and the other members of the family, especially the mother. One has to answer as quickly as possible the following questions: who are you, what are your strong and weak sides, what are you trying to communicate by shouting, crying, mimicry, and pantomimicry. When we know how to deal with our emotions, and start to support instead of blaming each other, then the time for closer contact and knowledge of each other has arrived.



OUR FIRST CONTACTS

We very often hear that when disabled children are born they are different, but nobody can describe and understand that difference. This being different means that such children have the same needs as all other children of the same age, but they require special conditions in order to fulfil them.

What children need most in this period is the love of their parents, and especially their mother. Mothers can manifest this love by holding children in their arms, hugging them, rocking them, and kissing them.

A mother show those feelings in a natural way, most often during nurturing activities and later on during playful activities. The more signals we send to children that we love them, the more confidence and the higher the self – esteem they will develop.

Touch plays a special role in our contacts with children. Their development and self-discovery and the discovery of their environment depends on how long our tactile contact with them lasted, and how intensively we touched the different parts of their bodies, and whether it was pleasant for them. Children learn in this way not only to receive feelings, but also to give them, by cuddling up, smiling, and looking into our face. So it is important to touch them in different ways; caressing, massaging, hugging, and rubbing with materials of different texture.

Touch is allied to movement: they usually coexist. A movement releases activity in children, it encourages them to discover the world, it makes them more self-reliant and independent. The physical activity stimulates the cognitive activity. It is important to hug children, turn them around, change their positions, rock them in a blanket or in a hammock and, if it is possible, put them to sleep in a cradle. We should start doing this in the early months of infancy. Tactile and motor activities are extremely important for children's awareness of their own bodies, and their general growth. Frequent tactile and motor contact enables children to learn that they've got different parts of their bodies, that they have different functions, and most importantly, it enables them to distinguish between themselves and other objects (things and persons). Those experiences have a therapeutic value: they soothe and harmonize children's feelings, and provide them with pleasant sensations, to which their health is by no means indifferent .

We should confirm our love in words, directed to our children. It is important to say how much we love them and why, and present them with the most beautiful expressions. It doesn't matter that children do not understand the meaning of the words: they get the meaning unconsciously, because our intonation, timbre, and the strength of voice are specific in such situations. The more we stay in touch with our children, the faster we will observe their developmental progress.

The overt manifestation of our love gives children a feeling of security. They tend to feel very helpless. Permanent contact with one loving person develops a gradual attachment in children and teaches them to predict the reactions and behaviour of that person. Then everything that can happen is to

some extent familiar to children. Only one and the same person (best a mother) who is a warm, accepting protector, who clearly makes demands and forbids some things, as well as granting some privileges, can create the environment which will stimulate the child's activities.

Children want to be close to another person from the first moment after birth. This feeling of closeness not only allows them to feel secure, but also encourages them to have a dialogue with the another person. Initially, communication with children has a physical-emotional character, and later a verbal one. The best situation for getting into close contact with children is breastfeeding. Children appease their hunger, but also experience the companionship, being a part of the mother. Nursing gives fulfilment to a mother. She and her child give warmth to each other, adapting their own movements, the position of their bodies, and harmonizing their heart-beats, in order to communicate as well as they can through this act.

Another form of dialogue is the exchange of looks and smiles. When parents and children smile to each other at the same time, they experience an unusual closeness based on emotional correspondence, known as „emotional resonance“. Close physical and emotional contact form a steadfast feeling of security, called „basic trust“, on which children will rely throughout their lives. It will enable them to believe that the world is a secure place, and that they can always meet friendly people there.

When we hear the first sounds of babbling, a new way of communication occurs. Most often we try to imitate those sounds, and children hearing themselves in us become fascinated and repeat this activity, sometimes with a greater degree of animation, accompanied by movement. Their joy becomes our joy, and the conversation takes on different shades and becomes extended. This way of influencing our children is known as „the method of mutual reflection“.

With time the first words will emerge in our conversation. Though we should speak clearly, in an articulated way, it is important to get in touch with our children by using the same words (even at the expense of correctness) that they use. Mutual understanding and comprehending intentions is essential. Correct speech should be used when we describe something to children, when we impart some knowledge or initiate contact with them. When they start to communicate something our response should be shaped in a similar way, that is to say in their language.

For the social development of our children it is important to respect their two basic needs: to be noticed and to have contact with their peers. We should acknowledge our children's presence in different situations and emphasise the effects of their activities, not necessarily evaluating their value. Giving such attention to children will enable them to acquire an elementary sense of their identity and their self-esteem, enabling them to realise who they are and accept themselves. Noticing the effects of children's activities, especially positive ones, will stimulate the „causative I" in children, i.e. the belief that they can influence their environment, change it, achieve goals, solve problems, and make decisions in their adult life. Children as social creatures need the constant presence of another person. During infancy the help of a loving and wise protector is indispensable. Later on when they become more independent they expect to have the company of their peers. They have to test their acquired skills and acquire new ones which are useful for community life.

Parents are not only the guardians who satisfy their needs by providing children with proper conditions of life and development, but also the first teachers to introduce them into the surrounding world. They encourage children to learn about the characteristics of different objects, they help to give them meaning, and teach them how to behave in different situations.

Disabled children need special help from adults. It is not an easy task, because one has to observe their spontaneous developmental inclination and teach them the different ways of stimulating that development. The usual, traditional knowledge is not always sufficient. Our first task when acting as teachers is to awaken children's activity, their curiosity about the world. In their closest surroundings there should be many stimuli working with different degrees of strength and frequency, but they should not endanger their security. In everyday life it might provide children with stimuli of different colours, sizes, textures, and sounds. Their surroundings should appeal to all their senses. When they display the first signs of independence, such as holding an object in a hand and manipulating it, and take their first steps, our help should include two things: preparing an environment for joint activities and discretely supervising their progress. The first task is the choice of a proper place, supplying it with suitable toys, objects, and elastic materials. The place where children are to play should be spacious, secure, and inducing good feelings. A floor, covered with a carpet or a blanket, is best. Toys suited to the age of the children (rattle-boxes, toys to bite, and later building

blocks, balls, cuddly toys), and also various useless objects which are not dangerous (paper wrappings, boxes, spools, etc.) should be of an appropriate size, intensively colourful, and emitting different sounds. The number and type of toys reserved for a meeting should be reduced to a few, otherwise children may have difficulties with concentration and focusing on an object and their attention will be distracted without finishing the game they started. In such a situation we should encourage children to keep playing, prompting new types of activity and leading them back to the lost or interrupted one.

Frolics play a very important role in games for the youngest (rolling on a blanket, flinging and tossing, galloping, dancing with a child in your arms). It not only gives joy, but also releases tension, teaches how to deal with unpleasant feelings, helps to get in touch with others, and also is good exercise for the whole muscular system. Providing that your doctor has no objections, you should encourage a child to frolic.

Apart from frolicking other manipulative games are also of great importance because they stimulate the general mental development of children. Though a child can manipulate any toy, it is still best to use flexible, elastic materials. Some of them are made of natural substances (water, sand, gravel, clay, granules and edible substances such as rice, beans, etc.); others are artificial (paints, different kinds of substances such as play-dough, Plasticine). Their advantage over toys is that they can be modelled in any way. With such substances we can induce very simple activities, such as pouring granular or water substances out of one vessel into another, and later on we can try to create an object with a more definite shape (for example a shape in the sand, or an animal in Plasticine). Such games inspire creativity and joy in children, and help to develop contact with others. It is important to practise manual skills with mentally disabled children. When they grow up, their future will mainly depend on what they can do with their hands. Skilful hands, especially fingers, will determine the quality of their cognitive development. By examining different objects with their hands and the help of their eyes, they learn about their qualities: their shape, texture, and size. By accumulating these experiences they form elementary opinions about animate and inanimate objects. When they later give words to those objects in future, they will achieve a higher level of development, and will start the long process of forming abstract ideas. Manipulative games prepare them for understanding quantities and numbers (especially during games with fingers, for example a game about a small magpie), and teach them how to compare, how to spot similari-

ties and differences (especially in constructive games like painting and modelling), and learn about basic mental activities. The mental development of a healthy child takes the same path as that of a disabled child, the latter however takes longer, some stages occur later and some will never be achieved.

Games with small children should have a spontaneous character, the choice of activities depending on the child. We should intervene when a child does not undertake an activity, or expects our help. Children ought to be ready for the game, i.e. they should not be sleepy, tired, or hungry. Their behaviour shows whether they want to undertake an activity or not. Apart from a game, also everyday situations such as eating, dressing, bathing and walking should teach them about the world. They get to know not only objects themselves, but their qualities and functions, etc. In every moment of mutual contact we learn something new. In the first years of existence of disabled children, our deep and thoughtful love and constant dialogue will determine their developmental achievements.

SHOULD WE START PRE-SCHOOL EDUCATION?

The pre-school age is a period of very dynamic changes in the development of all children. They gradually change from being helpless and de-



pendent creatures into more independent people. The majority of children start pre-school education in this period, which involves professional assistance with the child's development, widening his/her social contacts with peers on the one hand, but on the other hand breaking the ties with parents, especially with the mother during many hours of the day, and also the occurrence of many difficult situations with which he/she has to deal. Not all children can come up to those expectations. The process of adapting to nursery school is painful and difficult for nearly all of them.

All children have a right to pre-school education, but not all of them are ready to start it. Living in a community, fulfilling teachers' expectations, and a lot of independence in different situations: these are very difficult to cope with. If children get support, they gradually overcome the obstacles. For disabled children support means preparing a kindergarten for their reception and preparing both the children themselves and us – the parents.

Although in the process of preparing of a kindergarten for the reception of disabled children it is mainly the staff who should be involved, we should also take part as well. Sitting together with the future teachers of our children, we should outline their good and bad sides, and should once again trace their development so that teachers can properly understand their present behaviour. This co-operative learning about our children should last throughout the whole period of their kindergarten education. Secondly, we should work out an individual programme for their education, with the teachers. Not only because we know our children well, but also because we will be carrying it in our homes. And thirdly, if time allows us we should participate in the process of education, i.e. accompany our children in their struggles with all the new problems of their pre-school life, and at the same time we help and co-operate with the teachers.

Scientific research shows that the best teachers of children at this age are parents, and especially mothers. Their active participation in the process of pre-school education has an exceptional impact on the mental development of children.

Children themselves have to be ready to start pre-school education, especially in integrative groups. They have to achieve a level of social and cognitive development sufficient to cope with forthcoming demands. The ability to look after oneself (eating, dressing, signalling physiological needs), to adequately respond to teachers' instructions, to follow their directions, and the ability to live in a community using verbal and extra-verbal communica-

tion skills (children can express their needs with the help of words, gestures, and pictographs, etc.), not to mention good visual and motor co-ordination of a kind which allows children to partake effectively in different activities – all are very important.

As parents we have to be ready for any new problems that may occur at this time. Maybe we need to enlarge our knowledge within the pre-school and specialised pedagogical fields if we want to continue our teaching work at home. We should also get actively involved in the educational process because of our children's adaptational problems. We must accept undesirable changes in their behaviour, which are the symptoms of such adaptational problems, even though at first we can feel helpless when faced with them (negativity, contrariness, aggressive and destructive behaviour, isolation, regress, day or bed wetting, etc.).

The period of pre-school education is difficult for children and parents. Before taking a decision we should reflect well and undertake the preparatory, educational activities for children who are going to enter a new period in their lives. The choice of the time and form of pre-school education should depend on the psycho-social maturity of children.

Undoubtedly such an education is very useful for our children: it teaches them how to live among others, it stimulates their psycho-motor development, it prepares them for the new task – school education. Our child's adjustment to the new environment will be easier, if they start pre-school education when they are older (between 4 and 5) and if they spend only a few hours (4–5) each day at the kindergarten, at least at the beginning.

One must also remember that the pre-school education of a disabled child normalizes family life. All members, especially the mother, have more time for themselves, and are freed from problems and difficult emotions, to arrive at a more objective picture of their child's capacities and limitations.

Our child is going to school

Starting school education is very often a time of difficult emotions for parents. There is still a hope that everything might be fine, that their children will start to learn in a normal school, and that they will make use of the years of intensive rehabilitation exercises, learning independence and self-reliance in class, and that they will be able to be among their healthy peers...



The decision to start in a special school takes away all parents' hopes. The idea of such a form of education is considered by them to be the failure of a lifetime, and for that reason they try to change the decision, even though it is not always good for their children. The first move you should make is to go to a normal school and to a special school. Check what each of these institutions can offer your child. Check how many pupils there are in the school, how numerous the classes are, and whether the teachers will be able to work with your child. Then sit down and write down all the pro's and con's, but in the context of what is good for your child.

It happens quite often that a parent just says: „No!“ without even seeing the proposed institution.

The beginning of the school education of a handicapped child is difficult for parents for yet another reason.

Until now it was the parents who were responsible for bringing up and making a child more efficient. From now on the child will be stimulated by different people. Many questions arise. Will they do it well? Are they able to do it? Will they protect our child from failure? Sometimes it is very difficult to believe that others are able to guide our children and that they won't harm them. There is a temptation to undertake the whole task of education by yourself, without accepting others, even professionals.

After all... You should remember to detach yourselves from the duties of child-care from time to time. It is indispensable to your health. (see the letter 2). The school is a great chance for the parents to share the responsibility of stimulating the child's development and caring for him/her. It is time to accept that others also know how to help our children and our family. The school gives children something that parents cannot give – an opportunity of getting in touch with other children. That is why if parents are drawn to the possibility of educating their children at home, when they have an opportunity to be among peers, then the parents should seriously consider this point. The need for contact with others is considered to be innate, which is confirmed by research into the question of children's socialization. It occurs in all children, regardless of the degree of handicap. The lack of need to be in a group can signify that a child is shy, or is in a poor mental state, or has been affected by bad experiences after previous contact with his or her peers. Giving children a chance to meet with others, regardless of their age, is essential, because we want our children to live among people and to find their own place in a society.

There are no ready answers as to which school will be the most appropriate. It is widely known that it is beneficial for less developed children to have an opportunity to learn together with their properly developed peers. Yet one has to remember the good and bad sides of this. The fact that children will stay in a natural environment, among the colleagues from the closest neighbourhood is the argument for. If they get full support from the school and become fully accepted by their peers and their parents they will find their own place. But it can happen that emotional injuries caused by disappointments will not only lower children's general cognitive activity, and lead to undesirable defensive behaviour (lying and cheating), but will also engender neurotic disorders, and most often fears.

Integration classes within the context of normal schools might be a good solution. Those classes with a reduced number of pupils, with two teachers, including a special tutor, will enable the adjustment of the programme of teaching to the individual needs of the pupil. One has to remember, however, that children who start learning in such a class should not have too much undesirable behaviour. For this reason we should pay special attention to the situations where such behaviour occurs and teach our children how to overcome it. We should remember that a man living in society should follow certain rules and values. It takes longer for mentally disabled children to le-

arn how to behave according to rules, because of their weaker cognitive orientation in different social situations, as well as their lesser social experience due to their isolation. That's why they should acquire a code of behaviour in a very systematic way. The most efficient way is for parents to teach the existing principles and the desired values, especially by example. Parents should be natural models for their children. It is much more efficient than verbal influence. A child's situation is very disadvantageous if the basic educational functions are carried out only either in a kindergarten or in a school. Before our children start school education they should learn how to co-operate both with their peers and with adults. Each form of co-operation requires the establishment of certain rules, the exchange of opinions, and understanding the needs of others, to contribute to the control and adjustment of our own desires and behaviour. In this way we develop in children the internal need to treat others in the same way as they themselves would like to be treated. No matter in what school children begin their education, the parents should help them to develop those features of personality which will allow them to find their own place in a school society at the moment of starting education and becoming independent in adult life – after finishing school. E. Muszyńska (1991) underlines the fact that some features apply to the children's attitude towards themselves, while others to their attitudes towards others. Within the first group the development of independence, emotional resistance, optimism and self-acceptance is important. The second group concerns socialization in general, and especially the development of communicative and co-operative skills.

Independence is very often understood as the ability to be self-sufficient and to carry out the basic activities of daily life. The ability to control one's behaviour, i.e. setting goals, undertaking tasks and choosing ways of acting and taking decisions concerning our own person, is very often not included. It is very important to acquire the simple daily activities involving clothing, eating, as well as washing, cleaning, shopping, trying to use means of transport without the support of another person, doing homework, establishing social contacts with others, profiting from leisure time and money-management. Yet self-control and the capacity to make one's own decisions is even more important. Parents and therapists deprive mentally disabled people (often even when they are grown-up) of this right. Cunningham (1992) quotes a conversation with a 28-year-old woman with Down syndrome. Asked how she was doing, she said: „Thank you, nothing has changed; my parents

won't let me move out. I take care of them. I do the shopping and the housework. They very often say that they would be lost without me. The development of independence in guiding your own behaviour is an extremely difficult task. It requires parents to give children the freedom to choose a game or a companion, and to restrict their own role to discrete observers who only help with advice. Yet advice cannot be a command, nor an observation, nor interference. Parents will be forced all too often to let children experience the painful consequences of their wrong behaviour. The only thing they can do in such a situation is to teach their children the right response to failure. If children enter adulthood with this ability, then the question of what will happen to them when their parents are no longer available won't be such a painful one to face. The parents will have the certainty that they have taught their children how to live and enjoy life. Yet to achieve that other abilities are indispensable.

Emotional resistance occurs in difficult situations, but expresses itself in the readiness and ability to overcome them. The role of parents should be in providing children with positive experiences in handling such difficulties. They can, for example, make a problem less burdensome (if the children are away from home, they can make them less homesick by frequent visits), they can provide their children with knowledge and examples of how to behave in a difficult situation (by making use of literary examples), they can apply psycho- and socio-dramatic techniques (children adopt a given role in a difficult situation and later on analyse their own behaviour and its accompanying feelings and consequences). The emotional resistance of disabled children is also shaped by acquired experiences. According to a lot of research the following experiences have an impact on children's emotional resistance.

1. The child's socialization. Persons with a more pro-social attitude are more stress-resistant than egocentric ones.
2. The development of a cognitive sphere with a stress on positive self-awareness and a positive system of values which can give a meaning to life, in spite of the disability.
3. Activities developing physical and mental skills. Any illnesses, fatigue, irritation weaken emotional resistance considerably.

Apart from educational methods introduced above, the parents' attitude towards everyday difficulties and their approach to their children, as well as the relations between members of the family, shape their children's emotional resistance.

Optimism – a person tends to perceive everything according to his/her wishes and expectations, and has an inclination to ascribe positive values to the surrounding reality when it gives him pleasure. The parents should develop this feature in children in such a way that it will help them and not prevent the process of adaptation. E. Muszyńska (1991) suggests that parents show their children the facts, in order to prevent a passive waiting for a miracle, and that they reveal unfavourable information to their children gradually, taking into account their readiness to accept it. Let's remember that the atmosphere of optimism so indispensable to children's development should be cultivated in spite of everything. In letter of Martin's mother, the faith in a better tomorrow for her son and her whole family is so immense that it can move mountains. Her struggle for Martin would be impossible without such optimism.

Self-acceptance – is understood as a positive attitude towards one's own person and a positive evaluation of one's own capabilities. It is a condition not only of adjustment, but also of effectively withstanding one's own disability. In order that a child can achieve this, one has to help him/her to develop the ability of objectively recognising both his/her strengths and weaknesses, and also the ability to positively evaluate one's possibilities, especially those which concern overcoming the disability and which point in a direction that can separate the limitations of the disability from the fundamental values of positive living.

Socialization – comprises the development of two important abilities: getting in touch with others and acquiring a pro-social attitude and the ability to co-operate. In order to help disabled children to achieve these abilities one has to arrange situations which will provoke new encounters and experiences and enable them to gain knowledge and make them want to share this knowledge with others. Let us remember that praising children and showing an immediate interest in the things that children try to communicate, as well as reacting in a certain way, strengthens the child's willingness to get in touch with others. Co-operation in play, or in work, as well as physical exercises which require contact with another person, encourage and stimulate them to establish contacts with others. The larger the variety of those contacts, the greater the opportunities for fast and effective acquisition of communicative skills. Hence interpersonal relations should not be restricted to the home, but should also include contact with peers and adults. We should teach our children to abide by social and moral rules, to overcome the fear of being with

others, and to be active in order to be accepted by others. The acquisition of the above mentioned skills will enable handicapped children to find their own place in school society and will make those years something to be remembered and recollected positively not only by the children, but also by the parents. Try to choose such a school for your children, where their capacities and previously acquired skills will be noticed, and where the teachers and therapists will concentrate on helping them overcome their difficulties.

OUR CHILD IS GROWING UP

The period of adolescence is extremely difficult for both parents and their children. At this stage there occurs a tendency to search for one's own place in life and know oneself better. The process of searching and self-discovery, known as identity development, does not occur at the same time for everybody. Also the ways of getting to know oneself are different. Self-knowledge, together with self-evaluation, have been developing since childhood, yet they are mainly situational, depending on other people's opinions, and the results of their own actions and behaviour. Those experiences become gradually ordered and generalized and they enable children to observe in their own attitudes and feelings a regularity which becomes fundamental for their self-discovery. It is an extremely difficult period for mentally disabled adolescents, for it is then that they keenly realize their disability (I. Obu-



chowska 1991). Hence a frequent question comes up: What should the parents' attitude be to their children's realization of their lesser intellectual capacity. They should not hide this fact from the disabled, any more than from society. The disability should not be a source of embarrassment, because it is a matter of chance. We should discuss with our growing children their problems, advise them when they make decisions, and support them in their breakdowns. Yet we should do it in such a way that they will learn how to make their own decisions and guide their own life. Not until parents themselves realize that the ultimate happiness of a person does not depend on his/her intellectual level, but rather on his/her attitude to life and the ability to find in it daily satisfactions and joys which are possible on every intellectual level, will they be able to impart that truth to their growing children. The parents have to arm themselves with patience, because the time of their children's search for their identity very often takes the form of trying out parents' love, which can very often involve being provocative or even aggressive towards them. Adolescents test out their patience and leniency, but also by observing their parents' reactions children get to know themselves. Another way of searching for identity is the attempt to change oneself, experimenting with oneself through changes of hairstyle or dress style. Adolescents, regardless of their intellectual level, learn about themselves by discovering their own physical and mental capacities; their muscular strength, running speed, and the impact of their own sex on the opposite one. Hence it is important to propose types of activities, in which a disabled person can take a part and have the opportunity to achieve success as well as getting in touch with other peers.

OUR CHILD IS BECOMING A GROWN-UP PERSON.

All parents have difficulties in realizing that their children are slowly turning into adults. They think that their children have still got time to go before having an independent life, and that they are not mature enough to make their own decisions. Parents think that by guiding their children they will prevent them from failures and life's impediments. Especially when children are handicapped, there is a temptation to make them eternal children, because it is easier to protect them in this way. One does not have to worry whether they will safely get home, because they do not actually go out at all. One does not have to worry about children's problems at work, because they have not got any work. Finally one does not have to worry that they might be hurt by their

colleagues, because they do not get in touch with them. We parents, are always here to protect them. Yet the obsessive question always appears: „*What will happen if we are no longer here? Who will take over all the duties of caring for our disabled child?*” This question comes back more often with time and causes strong negative feelings and anxiety in parents. Parents seldom have a chance to learn about the vicissitudes of mentally disabled adults, nor about the experiences of their parents and families who were in a similar situation once. They are haunted by the vision of the „Institution” and it terrifies them because they have never had a chance to see such a place. The fear of the unknown is very strong in everybody, but becomes unbearable when it concerns somebody close to us. This fear is made even stronger by the fact that children won't know how to fight for themselves and will be dependent on others when the parents are no longer there. It cannot be denied that it is the family which is the best educational environment for the mentally disabled, and where parents place all their hopes for their children's future. When their healthy children's lives are settled, the parents should start to discuss such things with them, but not before. Otherwise they should not be burdened with the responsibility for their disabled siblings. One mother of a son growing up with brain paralysis, who also had a healthy son, said: „*We would like to raise them in such a way that they can always rely on themselves, and so they remember that they are one single family. Not until our healthy son becomes an adult, will he realize that he can give support to his disabled brother. But he already knows that he has a right to have his own life*”. Parents often do not realize that they should help their children to become adults, and give them the right to decide how to spend their own time and develop their interests, e.g. being active and sociable. This degree of self-dependence will have an impact on the future situation of mentally disabled persons, and the conditions of their lives.

A lot of mentally disabled adults develop hobbies such as the fine arts and theatre; other take part in different sports and recreational activities in their free time. Many try to use their leisure time for developing contacts with others. Some foster contacts in family circles; others join informal groups and organizations which function in their environment. The task of parents is to help children to choose the right form of activity and encourage them to spend time among their friends.

It is very important for mentally disabled people to take up a job. It serves a therapeutic and rehabilitating function; it prompts development; it opens up

possibilities of integration and new contacts with other people. Work evokes self-dignity, self-esteem, and self-respect in mentally disabled persons. By making decisions and solving problems they can achieve independence and self-reliance. It would be a cliché to remind someone that work brings satisfaction and pleasure only when it is suited to the capabilities of a disabled person and provides such a person with humane and appropriate conditions of work. That is why it is worth the effort of undertaking the task of choosing the most appropriate work for a mentally disabled person – it could be an institution for „sheltered work”, workshops for occupational therapy, or an activity-based club. The most suitable place would be one where a disabled person can feel needed and accepted.

I hope that introducing a few solutions for the adult life of mentally disabled persons will help parents to arrive, together with their children, at a decision concerning their future lot.

1. A mentally disabled person lives in a flat with a companion, possibly one of the siblings, or relatives, a friend of the family or a student. It is necessary to set up legal regulations concerning the rights and duties of the companion, and to ensure the possibility of changing the person if he/she does not come up to the expectations of the mentally disabled person.

2. A mentally disabled adult moves to the house of one of his/her siblings. This is a solution dreamed about by many parents, which lets them to enjoy their adult lives without worrying about the future of their mentally disabled child. One should discuss such a possibility with all the people involved – a disabled person might have their own reasons for rejecting such a proposition. If both sides agree, however, one must prepare them for being together. It usually happens spontaneously, but if not, one should look for frequent contacts, explain the duties and habits of the handicapped person, as well as the food that he/she likes to eat, the places where he/she visits and what can be his/her contribution in the new place.

3. Hostels – the „family substitution” houses function on the basis of substitute families, their tenants becoming integrated into the entire family life; they perform house duties together – do the shopping, clean, prepare the meals. They have the right to choose how they will spend their leisure time and they can take part in organized activities. A manager who plays the role of “father” is in charge of all activities, together with a small staff. In order to be accepted into the group basic skills in self-service and community life are required.

4. A mentally disabled person lives in a house in one of the *Arc* communities. These are smaller communities, with a very rich spirituality, where disabled people and their assistants share the impediments as well as the joys of daily life. This is a wonderful place for people with a deep religious life.

5. A mentally disabled person receives a place in an institution for the handicapped people. These are organized by foundations and associations for mentally disabled people. The organizers are strongly involved in work for the disabled and pay a lot of attention to the quality of life of their tenants.

6. A mentally disabled person lives in a social council house together with a parent. He/she has friends there, carries out occupational activities and lives with a close relative at the same time. When a parent dies the feeling of security is not so shaken, and the gap following the loss of the beloved person is more easily filled.

7. Institutions:

It is true that social institutions do not provide for basic human needs (a place to sleep, food, clothes, medical aid, elementary social security) in the same way as is done at home. Yet living conditions in these places have improved recently thanks to financial support. Institutions with their modern equipment more often resemble private houses. The importance of the independence of the disabled is stressed more often now. They have the right to have their own things, clothes, and to make choices concerning their self-sufficiency. They can choose how to spend their own time and they can take up a job. It helps them preserve their individuality, identity, and at least partial autonomy in the spheres commonly considered as intimate, private and personal. It is worth making the effort to find a place where all these needs will be respected. One also has to realize that the fact that a child lives in an institution does not necessarily mean breaking ties with the family. On the contrary, the family can help a lot during the period of the adaptation to the new place, and also create new opportunities for taking part in family life. Some parents visited their disabled children in an institution every day for thirty years, hoping that he would give them a sign that they matter to him. Martin's mother (letter 1) is close to her son too. Martin knows that he is not alone. If your child is to have a place in an Institution, try to look on the good side of this situation and do not think that it is the worst possible evil, because your prejudice will spread to your child.

We know that we have touched on some very difficult problems here, but by talking about them they become less burdensome. If we can solve them today, then there is a chance that nothing wrong will happen to our child and that we can just share the joy of still being together.

Not all mentally disabled people can achieve a high level of independence and social development. There are seriously disabled children among us, whose parents are especially worried about their future...

That is why we want to dedicate to you these words from Erikson-Tode's book, *The exam in Friendship* :

*Blessed are you who take the time
To listen to difficult speech,
For you help me to know that
If I persevere,
I can be understood.
Blessed are you who never bid me to "hurry up"
Or take my tasks from me,
For I often need time rather than help.
Blessed are you who stand beside me
As I enter new untried ventures,
For my failures will be outweighed
By the times I surprise myself and you.
Blessed are you who ask for my help,
For my greatest need is to be needed.
Blessed are you who understand that
It is difficult for me
To put my thoughts into words.
Blessed are you who with a smile,
Encourage me to try once more.
Blessed are you who never remind me
That today I asked the same question twice.
Blessed are you who respect me
And love me just as I am.*

HOW TO HELP YOURSELF

Raising a disabled child requires a lot of family resources: energy, time, and financial means. The parents most often have to change their life plans, and their mode of living hitherto. The enormous duties connected with continuous nursing, caring, educating, and therapeutic work drain the family's strength, and it can seriously influence their mental and somatic condition. Such a strain on the family can have a negative impact on the relation between the parents and the disabled child. Such an unfavourable atmosphere can cause negative, secondary changes in a child's development.

Each family with a disabled child should work out its own ways of dealing with the problems and difficulties which life brings. This process of learning and searching can be reduced by using other families' experiences who have found a way of overcoming the crisis, and have undertaken the difficult task of returning to normal life. The development of personal and social family resources will help to solve all the new problems constructively. Helping yourself most often includes five groups of requirements, which are worth undertaking for benefit of your family.

1. The concern for your own mental health.

The mother, especially should take care of her own mental health, because she pays the biggest physical and emotional price for bringing up a disabled child. Only an emotionally balanced mother, who guarantees security and brings joy into family life can create a favourable atmosphere for bringing up children.

Excessive concentration and total dedication to disabled children can seriously infringe upon their development. At least part-time work or charity work is advised for mothers, or participation in some sort of social life, recreational activity, and at least a few minutes of relaxation every day. The division of duties among members of the family, the help of volunteers (relatives, high school pupils from charity organizations), the assistance of a therapist will facilitate the organization of life in such a way that a mother will be able to find some time for herself.

2. The concern about the mental health of other members of the family, and especially the siblings of a disabled child.

The disabled children's siblings also have to pay a price. They often feel less loved, even rejected, and experience injustice and jealousy about the privileged position of their disabled brother or sister in the family. We should remember the needs of other children and direct words of love to them also.

3. Continuous improvement of your own psycho-educational skills.

In the upbringing of a disabled child one should not rely on common knowledge, traditional wisdom and one's own intuition. Medicine, psychology, and special educational principles offer the knowledge which will enable us to guide our children's development, to understand their developmental tendencies better and to find effective ways of supporting them.

We have to improve our educational skills through self-instruction, and partaking of different forms of training and rehabilitative instruction.

4. Regular contact with professionals.

Bringing up disabled children requires the guidance of professionals from the earliest stages of their development. The type of help will depend on the children's age and the progress of their development. This assistance is needed from the moment of birth in order to restrain our emotions in our first contact with the child. The specialist from Early Intervention Centres will show us how to treat our children in the first years of their life, and later on we will be able to turn to various clinics and educational institutions.

5. Regular contacts with support groups.

These create bonds, and give support and models of behaviour in different situations. It can be a parents' association for children with similar developmental problems, a religious community, or a group of families based on mutual aid.

Each person is the best therapist for himself or herself. He/She unconsciously takes steps which help to effectively solve the difficult problems of life. Recognising the mental and spiritual resources of your family (vital forces, emotional balance, the system of the accepted values, self-esteem, mutual understanding and support, faith), their continuous cultivation and their development, and the active search for the assistance of professionals and people willing to help, are the most effective ways of dealing with the situation, as parents of a disabled child.

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Problems taken in her research and theoretical reports refer to personality development and social competencies of handicapped children and to possibilities of supporting this development through psychotherapeutic and stimulation activities.

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