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## **The role and significance of home in the process of rehabilitation of a child with mental retardation**

### **Introduction**

As a natural and popular institution, family is recognised as one of the most important values in human life. It fulfils all the functions related to care, education, teaching and socialisation. For many people, family becomes the sources of inspiration for all their actions. It is seen as the references point of their life as individuals.

Family members have a feeling that they belong together and this feeling supports them in their individual aspirations. Thank to the family, individuals humanise and socialise, and then integrate and identify with the society.

According to J. Mariański, as a part of socialisation and educational processes in family, values, standards and role models are transferred and, in a way, family acts as the agent between the individual and the society in respect of transfer, perception and acceptance of cultural content/ The content transferred also include those that provide a certain definition of the good and the evil.

Family as an institution that acts as the agent in transfer of moral values is irreplaceable; moreover, family upbringing in respect of the morality is of primary and incomparable significance. The author emphasises that understanding of transferred values is not only a cognitive process but mainly involves practical experience and beliefs, while transferred values concern communication i.e. bilateral dialog between parents and children<sup>1</sup>.

On the other hand, M. Ziemska perceives family as the source of human personality; in close interactions with his or her mother, father, siblings or grandparents, the child develops basic psychological functions and shapes the structure of his or her personality, whereas parents are role models for the child owing to whom he or she acquires the modelling process. The process is subject to acceptance of such trends towards the behaviour the child sees in his or her environment. The trends are reinforced by positive emotional relations of the child with the parents and the desire of the child to become like the parents<sup>2</sup>.

Therefore, the role of family in development and educational formation of child's personality is enormous and irreplaceable by any other social institutions. According to J. Brągiel, the strength

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<sup>1</sup> Mariański J., *Młdzież między tradycją i ponowoczesnością*, Lublin 1995, p.279

<sup>2</sup> Ziemska M., *Rodzina a osobowość*, Warszawa 1979, p.5

and nature of his or her action results from:

- social action of the parents on the child from the earliest stage of his or her life, when receptivity for the actions is much higher, and the actions are of a frequent and long-term nature because the individual is related with the family for the whole life;
- -actions of the parents on the child based on the emotional relationship with the child, which is even intensified by satisfying child's needs and, in consequence, ensures their high effectiveness;
- -the fact that the parents shape the child in an intentional and unintentional manner but can reinforce their actions by a system of penalties and rewards;
- -from the fact that parents are role models for the child, thus he or she tries to imitate them in an intentional and unintentional manner<sup>3</sup>.

Family has many functions visible from the point of view of tasks performed for the society and for family members, which is directly related to satisfaction of their biological, economic and psychosocial needs.

Among the functions of family for the society and apart from the procreative, socialisation and economic function, M. Ziemska highlights the psycho-hygienic and enormously significant educational function<sup>4</sup>.

According to I. Obuchowska, family upbringing has his or her characteristics and, in comparison with educational processes in institutionalised conditions, differs mainly in the emotional layer in which three basic values can be distinguished:

**1. Spontaneity** – very frequently resulting from direct educational actions that do not submit to the environment and are considerably based on parents' moods, which may rust in minor mistakes in education but, at the same time, ensures immediate correction of child's behaviour. Spontaneous educational actions of the parents make the child feel their intentions are genuine, as well as evoke openness to communication, expressing oneself, and child's thoughts and feelings. The unique atmosphere of home, the emotions, worries and hopes experienced together impress on child's psyche, which is much more effective in respect of shaping his or her personality than any institutionalised educational syllabus.

**2. Empathy** – as an attitude of family upbringing, means parents "getting into the spirit of" child's needs and emotions. As the family environment is an area where empathy is experienced and expressed, children learn to show it and feel safe.

**3. Intimacy** – is a property of family upbringing because specific educational actions related to family members are secured against outsiders and, as they are often related to family tradition, unclear from the outside. In consequence, the intimacy of family life may intensify the emotional

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<sup>3</sup> Brągiel J., *Zrozumieć dziecko skrzywdzone*, Opole 1998, p.33

<sup>4</sup> Ziemska M., *op.cit.*, p.38-39.

bond in family<sup>5</sup>.

As emphasised by John Paul II, family “is the first and privileged environment of education, experience of brotherly life, and various forms of love and solidarity. Family life teaches openness, kindness and respect for neighbours who should always find the due place in our hearts<sup>6</sup>.”

### **Situation of a family that brings up a child with disability**

The information about child’s disability can surely be recognised as a situation that connotes many dramatic events in family. Most frequently, this is such an intense experience for the parents that it is even sometimes referred to as a psychological shock: the more intense, the higher and more serious the disability.

Related literature shows that, having received the first piece of information about child’s disability, parents are subject to such intense negative emotions that these are referred to as shock. The following stages of psychological experience of the parents are related to initiation of various psychological defence mechanisms against such feelings as despair, fear or irrational guilt. There may be a willingness to reject the child or find the guilty of his or her disability. The final stage is the phase of constructive adaptation to the situation characterised by recovery of ability to act for the good of the child. Unfortunately, there are few parents that can reach the balance unaided without any help of others in order to see their situation in a rational way, vigorously seek help, and take actions for the good of the child independently<sup>7</sup>.

It should be emphasised that long-term negative emotions and problems difficult to solve may result in formation of unwanted attitudes of the parents towards their own child and the environment. These may include overprotectiveness or excessive demands, indifference or even rejection. The so-called *burn-out syndrome* occurs in extreme cases. His or her characteristic symptoms include: resignation, energy loss or even total psychological and physical exhaustion resulting from intensive care over the child, the sole responsibility for his or her lot and loneliness<sup>8</sup>.

According to H. Borzyszkowska, attitudes of parents determine their relation to the disabled child, which may be:

- appropriate if the parents realise child's disability and face him or her with expectations adapted to his or her abilities, try to activate him or her and make him or her independent,
- overly lenient if the parents treat the child as ill-fated and try to make it up to the child by excessive care and affection, and expect nothing from him or her,

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<sup>5</sup>Obuchowska I. (ed.) Dziecko niepełnosprawne w rodzinie, Warszawa 1991, p. 13-14.

<sup>6</sup>“L'Osservatore Romano”15:1994 no. 3, p. 36.

<sup>7</sup> Domaredzka-Malinowska E., *Rodzina dziecka niepełnosprawnego*, (in:) *Wybrane zagadnienia z pedagogiki specjalnej*, ed. Tomasiak E., Warszawa, 1997, p. 71-72.

<sup>8</sup> Gałkowski T., *Dziecko autystyczne w środowisku rodzinnym i szkolnym*, Warszawa 1995, p. 82.

- overly demanding if the parents shut out the thoughts about child's disability, expect him or her to do much more than he or she can do and punish him or her for unfulfilled tasks,
- indifferent if the parents realise child's disability but see no possibilities of his or her development and, in consequence, no point in taking any actions<sup>9</sup>.

Attitudes of the parents towards the environment are also very important in case of a child with a disability. Their nature depends on the relations between the family and the environment they live in.

As suggested by A. Twardowski, parents may accept either an isolation or integration attitude. In case of the isolation attitude, the parents strive for withdrawing from social relationships and do not initiate new ones. It manifests, among others, in reduction of contacts with family, breaking ties with friends, withdrawal from social life, lack of contacts with neighbours and colleagues (e.g. at work). In case of the integration attitude, the parents strive for maintaining the social relationships developed so far and sometimes also for broadening them. Parents accepting this attitude often take active part in various associations and organisation that help children with disabilities and their parents<sup>10</sup>.

Child's disability usually deteriorates the economic situation of the family. The majority of mothers need to leave their jobs to handle upbringing. At the same time, expenses increase because a disabled child requires (often long-term) treatment, exceptional care and special educational procedures. A flat is another part of the living conditions of the family.

The fact that family has a flat does not necessarily determine positive effects of child's education but certainly is a basic precondition. A favourable residential situation ensures that the child has his or her own place to play or learn where he or she feels safe<sup>11</sup>.

According to studies, the air and psychical atmosphere of family are essential for comprehensive and normal development of child's personality. Parents that are confrontational, nervous and often antagonised do not ensure child's security but can also inhibit his or her development<sup>12</sup>.

The presence of a disabled child in family also changes conditions of development of his or her healthy siblings. A healthy child sees how much time and effort of the parents is spent for the disabled brother or sister and, in consequence, may feel neglected and limited in his or her rights and privileges. He or she may feel tired by excessive involvement in care over the disabled child. It is very typical that the fact of having a disabled sibling is the reason his or her shame in contacts with peers' attitudes of whom he or she is particularly sensitive.

<sup>9</sup> Borzyszkowska H., *Dziecko upośledzone w rodzinie*, (in : ) *Pedagogika rewalidacyjna*, ed. Hulek A., Warszawa 1980, p. 369.

<sup>10</sup> Twardowski A., *Sytuacja rodzin dzieci niepełnosprawnych*, (in:) *Dziecko niepełnosprawne w rodzinie*, ed. Obuchowska Warszawa 1991, p. 44.

<sup>11</sup> Twardowski A., op.cit., p. 47.

<sup>12</sup> Wojciechowski F., *Dziecko umysłowo upośledzone w rodzinie*, Warszawa 1990, p. 56.

According J. Kruk-Lasocka, the attitude of the healthy child to the disabled child may be created under the influence of positive or negative position of the peer group towards the disabled. However, similarly as in case of healthy children, parents have the largest impact on relations between the healthy child and the disabled sibling. Showing acceptance to both children and facing them with similar expectations (adapted to the abilities of the disabled child) forms stronger bonds between the siblings<sup>13</sup>.

To sum up, the situation of a child with mental retardation in family results from interactions of the complex system of family's emotional, social and economic structure and educational situations caused by individual features of the disabled child<sup>14</sup>.

### **The role of the parents in the process of rehabilitation of a child with mental retardation**

Significant changes in treatment of development needs of mentally retarded children in the context of family rehabilitation have recently occurred. The passive and anticipating attitude of parents towards professional efforts taken towards the child is a thing of the past. It is replaced by their active participation in the process of treatment and rehabilitation.

The idea results from political and social transformations of the state in which the objectification of his or her citizens is the basic attribute of democracy.

“The state has abandoned the principle of care over the family and developed another principle: of supporting the family. The fundamental responsibility for directing one's life is the decision of a given individual or a social group e.g. family. Initiative, independence and autonomism are principal privileges of citizens and social groups, whereas supportiveness of the state consists mainly of providing them with resources and tools”<sup>15</sup>.

According to F. Wojciechowski, it has been recognised beyond doubt that family is a rightful subject that should actively cooperate with specialists in planning treatment, rehabilitation and educational actions. The quality of the cooperation more frequently becomes the evaluation criterion of parents' educational culture and the general family function.

The author emphasises that parents have obligations towards the child stipulated by law and act on his or her behalf in various institutions and communities. The aforementioned issues particularly correspond to individuals suffering from developmental anomalies such as children with mental retardation<sup>16</sup>.

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<sup>13</sup> Kruk-Lasocka J., *Światło i Cienie*, 1996, no. 2.

<sup>14</sup> Dykciak W., *Wychowanie i rehabilitacja dzieci głębiej upośledzonych w rodzinach oraz w placówkach wychowawczo-rehabilitacyjnych*, Warszawa 1969, p. 10.

<sup>15</sup> Villa F., *Polityka społeczna, demokracja i praca socjalna*, Kraków 1997, p. 25.

<sup>16</sup> Wojciechowski F., *Problemy niepełnosprawności dziecka w pedagogice rodziny -wybrane zagadnienia*, (in:) *Człowiek niepełnosprawny w rodzinie i w środowisku lokalnym*, ed. Maciarz A., Janiszewska-Nieścioruk Z., Ochonczyński H., Zielona Góra 2001, p. 61.

A child with mental retardation needs special assistance from his or her parents, commensurate to the type and degree of retardation. He or she requires individual treatment and his or her development largely depends on the environmental conditions and appropriate satisfaction of his or her needs by the parents. Provision of optimum development conditions for a disabled child requires high educational culture of the parents expressed by the acceptance of the child, responsibility for his or her development and the ability to satisfy his or her needs. Parents need to understand that, apart from needs demonstrated by all children, this particular child had additional specific needs that have to be satisfied<sup>17</sup>.

O. Ivar Lovaas, author of *Nauczanie dzieci niepełnosprawnych umysłowo*, reflects on the significant role of the natural environment i.e. family in rehabilitation of a child with mental retardation. He claims that, since the behaviour of the child affects the surrounding he or she lives in and learns and the surrounding consists of several environments (a school, home, neighbourhood, etc.), then if we expect maximum progress of the child, the whole surrounding should play the educational and therapeutic function. Moreover, the natural environment i.e. family has developed for several thousand years and holds certain wisdom in respect of teaching, even if this is not always visible<sup>18</sup>.

Taking into account the responsibility of the parents and their subjective role in the rehabilitation process of the child, we should point out the factors that condition their active participation in the rehabilitative and therapeutic process. Undoubtedly, the principal issue is the availability of various forms of specialist help and the accompanying security that enable easier adjustment for new obligations and specific needs of the child. In particular, parents' good knowledge of the system of care facilities as well as their own organisational creativity in using the help offered become of utmost importance. In such a case, a positive cooperation is established between specialist establishments and parents.

Help provided to a family that brings up a child with mental retardation, according to A. Maciarz, should be comprehensive to the full and comprise the following four scopes of family support:

- psychological-emotional support,
- social-service support,
- care-educational support,
- rehabilitative support<sup>19</sup>.

Apart from institutionalised support, the role of parental initiative has increased recently. Therefore, as a part of an environmental social system, the rehabilitation resources of family as the primary group and the support group are expanded and, in the context of system solutions, parents share

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<sup>17</sup> Tucholska S., *Percepcja rodziców przez dzieci upośledzone w stopniu lekkim*, "Szkoła Specjalna" 1998, no. 3.

<sup>18</sup> Lovaas Ivar O., *Nauczanie dzieci niepełnosprawnych umysłowo*, Warszawa 1993, p. 11-12.

<sup>19</sup> Maciarz A., *Wspomaganie rodziny w wypełnianiu podmiotowej roli w wychowaniu i rehabilitacji dzieci*, (in:) *Podmiotowa rola rodziców w rehabilitacji dzieci niepełnosprawnych*, ed. Kostecki R., Maciarz A., Zielona Góra 1993.

responsibility for rehabilitative treatment results nearly as much as professional rehabilitation therapists. Parents have the right to decide which offers and proposals of specialists they want to accept and use. This open cooperation and networking based on partnership between parents and the professional assistance system is the basis for the appropriate program that support the development of disabled children<sup>20</sup>.

B. Wright comes to the essential conclusion that “parents and rehabilitation therapists need to cooperate to enable the parents to learn what is best for health, education and welfare of children suffering from a disability; therefore, rehabilitation establishments for children have to act through and with the parents”<sup>21</sup>.

### **Rehabilitation of a child with mental retardation at home – reflections of the mother**

Filip – age 8, mild mental retardation, participation in a therapeutic-rehabilitative program in the Psychological and Pedagogical Counselling Centre.

*My activities with Filip were always well-planned. Our program took into account imitation, perception, fine motor co-ordination and skills, cognitive work and active speaking. From imitation of movement of hands, touching body parts; through sorting, pouring, matching objects with images; to blowing games: we went forward step by step.*

*I was happy about every correct response, hugged him, clapped my hands or gave him something as a reward. I never punished him and we finished as soon as I noticed that he would not bear any more. I always finished with an easier task to ensure successful conclusion. There had to be a lot of various toys at home as he got tired with each of them quickly. Apart from pictures, puzzles and didactic games that I managed to buy, I used a lot of natural resources such as wood, salt paste, sand and water.*

*I learned to see stand-out toys in shops. I usually knew how they would affect Filip’s learning and how they could be used. The newness and appearance of toys stimulated my son and contributed to his development.*

*I paid a lot of attention to all everyday activities. I spoke to him while he was eating, dressing up and washing. I repeated each command until it produced an effect, several times, e.g. “Filip, put on the hat.” If he did not want to do it despite numerous repetitions, I helped him. When he was very impatient or if I was overly tired, I gave him no orders. I followed the rule that each command had to be carried out. When he objected, I pretended not to hear it and repeated calmly the same*

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<sup>20</sup> Wojciechowski F., op.cit. p. 63.

<sup>21</sup> Wright B.A., Psychologiczne aspekty fizycznego inwalidztwa, Warszawa 1965, p. 316.

*command. I tried to break his stubbornness by cheering him through tickling and frolicking; it usually worked. The more consistent I was in my actions, the easier it was. I noticed that he reacted best if I spoke calmly and used very short sentences. Impatience brought opposite results: shouting, reluctance and leaving.*

*We also wanted to furnish Filip with new experience and get him used to normal behaviour in public places. Our visits to Wrocław were a perfect opportunity to do it. My husband carefully planned our stay in this beautiful city and he was our guide. We always tried to stop by the zoo and the botanical garden. I always took some food he liked (e.g. Danone cottage cheese); we stopped on a parking lot and we called it a picnic. After several trips, Filip already knew what needed to be placed in the basket for the journey. We sometimes visited McDonalds' where Filip would get a Happy Meal with a toy. It was a great adventure for my son. My husband talked about each new place in a very accessible and comprehensive way. We always had a map of each trip. We often emphasised that our country was Poland and that Filip was Polish. While driving, we specified the direction we followed e.g. right or left. Each new place we visited left a trace in Filip's memory. We realised that it was our emotional support that our son needed most; normal functioning would be much more difficult for him without it.*

*What was the most important thing I had to change in myself?... I had to approach Filip as positively as I possibly could. Obviously I loved him, but I also realised that I had to grow to like him the way he was, accept him, and share his happiness and sadness. I could not fake it; besides, it would be impossible as we spent together a lot of time, day after day.*

*Finally, I ceased to be impatient, irritated and feel disappointed when something went wrong. I tried to understand what path we had to follow to succeed again. I wanted him to be satisfied and believe he could do something by himself. Gradually he began to seek praising when he was successful, clasped his hands and showed his happiness with a loud laughter.*

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### **Abstract**

Family is the first social environment of each person where education naturally begins. Upon birth, each individual meets specific customs, opinions and values in his or her family. The meaning and role of family in education and the whole development of the child increases when discussing a child with mental retardation. A mentally retarded child needs special assistance from his or her parents, commensurate to the type and degree of retardation. He or she requires individual treatment and his or her development largely depends on the environmental conditions and appropriate satisfaction of his or her needs by the parents.

Significant changes in treatment of development needs of mentally retarded children in the context of family rehabilitation have recently occurred. The passive and anticipating attitude of parents towards professional efforts taken towards the child is a thing of the past. It is replaced by their active participation in the process of treatment and rehabilitation. It has been recognised rightful subject that should actively cooperate with specialists in planning treatment, rehabilitation and educational actions.

### **Rola i znaczenie domu rodzinnego w procesie rewalidacji dziecka z upośledzeniem umysłowym**

Rodzina jest pierwszym środowiskiem społecznym człowieka to w niej w sposób naturalny rozpoczyna się wychowanie dziecka. Człowiek przychodząc na świat zastaje w rodzinie określone zwyczaje, poglądy i wartości. Znaczenie i rola rodziny w wychowaniu i całokształcie rozwoju dziecka wzrasta, gdy mówimy o rozwoju dziecka z upośledzeniem umysłowym. Dziecko z upośledzeniem umysłowym potrzebuje od rodziców specjalnej pomocy, proporcjonalnej do rodzaju i stopnia upośledzenia. Wymaga ono indywidualnego traktowania, a jego rozwój w znacznym stopniu zależy od warunków środowiskowych i właściwego zaspokajania przez rodziców jego potrzeb.

W obecnej rzeczywistości nastąpiły zdecydowane zmiany w traktowaniu potrzeb rozwojowych dzieci z upośledzeniem umysłowym w aspekcie rodzinnej rewalidacji. Odchodzi się od biernej i wyczekującej postawy rodziców wobec podejmowanych w stosunku do dziecka profesjonalnych oddziaływań, na rzecz ich aktywnego udziału w procesie terapii i usprawniania. Uznano, że rodzina jest pełnoprawnym podmiotem, który winien aktywnie współpracować ze specjalistami w programowaniu oddziaływań leczniczych, rehabilitacyjnych i wychowawczych.