

mgr Małgorzata Sikoń

**Polish Association for Persons
with Mental Handicap is public Benefit Organization**

Kołobrzeg

Family with an intellectually handicapped child

Family is the first and the most sustainable socio-educational environment of a child. A child coming to this world takes the place set by the society. The closest environment of a child supplies him with the basics to assimilate more and more new skills, gain consecutive experience that will affect his or her daily life. The most important and the nearest environment of a child is the family. It is family that cares about supplying the stimuli necessary to develop skills and satisfy needs of a child¹.

Z. Tyszka defines the family from the point of view of a group and the bonds linking family members, as "the community of people interrelated by the bond of marriage, kinship, close relation or adoption"². F. Adamski describes the family as "a social group, where the family is a spiritual union of a narrow group of people, clustered in a common hearth and home by the acts of mutual assistance and care, based on faith in true or presumed biological relations, social and family tradition"³. On the other hand, J. Rembowski describes the family as "small and at the same time initial group with a characteristic organization and a specific structure of roles among different members, bounded with mutual moral responsibility, aware of its own distinction, having its own traditions and habits, united with love and accepting one another."⁴

D. Goleman calls the family life "the first school, in which we learn what to feel for ourselves and how others will respond to our feelings, what to think of these feelings and what choice of

¹ A. Franczyk, K. Krajewska, *Program psychostymulacji dzieci w wieku przedszkolnym z deficytami i zaburzeniami rozwoju*, Kraków 2005, p. 20.

² Z. Tyszka, *Socjologia rodziny*, Warszawa 1976, p. 74.

³ F. Adamski, *Socjologia małżeństwa i rodziny*, Warszawa 1984, p. 21.

⁴ J. Rembowski, *Więzi uczuciowe w rodzinie*, Warszawa 1972, p. 83.

possible reactions we have, how to read hopes and concerns"⁵. Thus the parents must adopt an active attitude towards family life, enrich their knowledge and broaden the experience, on the basis of which they will be able to cope with numerous tasks and duties. The fulfilment of specific tasks is linked with the functions carried out by the family⁶.

M. Ziemska claims that "the family as a basic social group fulfils essential functions in society's interest, satisfying mental, emotional and social needs of its members at the same time. Therefore, it fulfils two types of tasks: towards society and towards individuals included in itself"⁷. The author distinguishes five functions of the family: procreational, production, service – protective, socializing and psychological. Z. Tyszka presented a more extensive and exhaustive classification of functions of the family distinguishing four groups of functions carried out by the family, and, in each group, proper component functions⁸.

I. Biopsychical functions:

1. Procreational function, consists in fulfilling parental, emotional needs of the partners in marriage and reproductive needs of the society.
2. Sexual function, consists in fulfilling socially accepted forms of sexual intercourse of the married couple.

II. Economic functions:

1. Material – economic function, satisfies the material needs of the family members;
 - production subfunction, the family is in the possession of a separate production workshop and is at the same time its production staff;
 - earning subfunction serves to provide the family with the means for living;
 - economic subfunction, consists in gathering fixed material goods, necessary for the family existence (apartment, household appliances, etc.);
 - service – consumer subfunction, consists in performing of all service-oriented work (mainly physical) necessary for functioning of the family members.
2. Protective – safeguarding function, consists in physical and material safeguarding of those family members who are entirely or partially deprived of the means for living or are physically disabled and require attention.

III. Socio-defining functions:

⁵ D. Goleman, *Emotional Intelligence*, Poznań 1997, p. 296.

⁶ G. Gunia, *Pomoc i poradnictwo rodzinie dziecka z wadą słuchu* [in:] *Dziecko z trudnościami w rozwoju*, ed. S. Mihilewicz, Kraków 2005, p. 105.

⁷ M. Ziemska, *Postawy rodzicielskie*, Warszawa 1979, p. 233.

⁸ Z. Tyszka, *Socjologia rodziny*, Warszawa 1976, p. 61–69.

1. Class function, consists of class affiliation, determining social position of the family members in the structure of the society.
2. Legalization – control function, authorization of certain behaviour and activities, consistent with the models valid in the family, supervision of the family member conduct by other members, in order to prevent possible violation of norms and models adopted by the family.

IV. Sociopsychological functions:

1. Socializing function, consists in introducing the child into the world of culture of a given society, preparation for unaided performance of social roles and interactions of the personalities of the partners in marriage.
2. Cultural function, consists in inculcating norms and the value scale in the young generation, transferring cultural heritage, and teaching the young generation to pay attention to the aesthetic experience of the family.
3. Recreational-social function, that is creating the family home as a place for rest, care of all the members for good atmosphere in the family and establishing social contacts by the persons that the family includes.
4. Emotional – expressive function, that is fulfilling the psychical and emotional needs and shaping the skills to express one's own personality.

The mentioned functions and tasks of the family can be, according to the assumptions of H. Izdebska (1979), divided into material and spiritual ones. The first group is responsible for the delivery of the means necessary to survive, health protection and material benefits to the offspring. On the other hand, spiritual functions cover mainly educational tasks⁹.

Concerning the family, in which an intellectually handicapped child is born, one should emphasize that the appearance of such a child in the family causes a major change in the way and quality of its functioning. It is the change of plans, dreams, beliefs about the future. To the parents it is difficult to come to terms with the thought that their child is handicapped. That is why it is important to fully accept the child in a family environment, without this the parents will not be able to raise their child.

It is beyond doubt that the birth of an intellectually handicapped child results in a crisis in the functioning of the family. Any former plans are being changed, the parents have to reorganize their life, change the social roles they used to perform, solve new problems. W.

⁹ G. Gunia, *Pomoc i poradnictwo rodzinie dziecka z wadą słuchu*, [in:] *Dziecko z trudnościami w rozwoju*, ed. P. Mihilewicz, Kraków 2005, p. 107.

Wolfensberger (1972) distinguishes three succeeding crises: a novelty crisis – characterized by the occurrence of shock after the birth of a handicapped child, having to change life plans, a crisis of personal values – the occurrence of a conflict of feelings "love of my child" and "rejection of a handicapped child", overprotective and rejecting attitudes and finally the last, lasting until the end of life – a real crisis – related to struggling with difficulties of daily life¹⁰. Many researchers signal the presence of permanent stress troubling the parents bringing up intellectually handicapped children. Here are some of the negative emotions:

- fear connected with constant life and health risk of the child,
- anxiety about his or her development and future,
- feeling of confusion and uncertainty as to the principles of conduct,
- solitude,
- monotony of life dominated by responsibilities and the lack of prospects,
- the impression of being stigmatised,
- irrational sense of guilt,
- sense of harm and loss,
- condition of constant mobilization connected with having to be always ready to cope with sudden and atypical situations,
- tiredness of all the feelings mentioned above.

Overcoming negative experience requires the assistance of constant mental support from outside.

The raising of every child requires competence. Care and raising of an intellectually handicapped child, and especially one whose difficulties and limitations are global, require particular preparation. Knowledge and skills should cover, among others:

- health care and rehabilitation,
- raising and education,
- conditions favourable to the stimulation of mental, personal, and social development of the mentally handicapped,
- preparation of work or occupation for an adult mentally handicapped person,
- the ability to formulate diverse expectations towards a mentally handicapped child, young man and adult,
- orientation in commonly available and specialised social resources and terms of using them (health, rehabilitation, education, work, culture, service centres etc.),

¹⁰ P. Kowalik, *Upośledzenie umysłowe. Teoria i praktyka rehabilitacji*, Warszawa – Poznań 1989, p. 188 – 189.

- orientation as to the rights and benefits and principles of using them,
- the technical, pedagogical and other assistance possible to obtain,
- information about associations of the parents with similar problems,
- dealing with the stress¹¹.

The lack of knowledge about the essence of disability of a child as well as the lack of any experience in nursing and caring over the child, additionally results in the feeling of being helpless and solitude of the parents of an intellectually handicapped child. Immense sense of fear, the lack of prospects of keeping the child alive and any clear concept of raising the child as well as the stress caused by having to provide the child with a particular type of attention, to which the parents are not ready, takes away their peace, all joy and the will to live on, destroys all plans for the future, by planting in their hearts and minds the sense of harm, revolt, grief and a great loss¹².

After giving birth to an intellectually handicapped child, the woman is usually forced to give up professional life in order to look after the child. Tired with day-to-day work at home, taking care over her handicapped child, inability to realize previous professional plans she feels overburdened by duties and problems falling onto her. This may result in misunderstandings in the family, continuous frustration, a syndrome of burning up the strength and disintegration of the family¹³.

It is usual that one of the parents of an intellectually handicapped child, most often the mother, gives up professional work, ambitions, interests in order to devote her time to the child. This situation is extremely frustrating. This is why it is important, in addition to exercising care over an intellectually handicapped child, to extend care over his or her parents who are not ready for the situation, in which they are, neither in psychical, nor competence terms. They experience shock, despair after the diagnosis and long lasting stress. Immediate, long-term, professional psychological help as well as counselling and education are necessary. Most often however, the parents do not receive the necessary mental support. A problem is also the lack of information, briefing and counselling regarding the stimulation of the development of the child, correct nursing and solving parental problems. After all, the

¹¹ K. Mrugalska, *Osoby z upośledzeniem umysłowym*, [in:] *Osoby upośledzone fizycznie lub umysłowo*, ed. K. Mrugalska, Warszawa 1996, p. 65.

¹² E. M. Minczakiewicz, *Wsparcie społeczne rodziny jako czynnik modelujący i kształtujący więzi w rodzinie wychowującej dziecko z głębszą niepełnosprawnością intelektualną*, [in:] *Roczniki Pedagogiki Specjalnej*, Volume XII, XIII, ed. J. Głodkowska, Warszawa 2002, p. 269, 270.

¹³ M. Sekułowicz, *Matki dzieci niepełnosprawnych wobec problemów życiowych*, [in:] *Roczniki Pedagogiki Specjalnej*, Volume XII, XIII, ed. J. Głodkowska, Warszawa 2002, p. 438.

sense of safety is so important, this could be provided by a complex, constant care and comprehensive mental support, and in special cases – specialized psychotherapeutical or psychiatric help, the improvement of competences, counselling, including family, life and legal advice as well as enabling contacts with other parents in a similar situation.

Mothers giving birth to intellectually handicapped children as early as in the hospital, after birth, should be provided with care of a psychologist, receive reliable information regarding the disorder in the development of the child, all necessary tests as well as a list of institutions involved in early, multi-specialist intervention.

I would like to end the above discussion with the words of one of fathers of an intellectually handicapped child: "there is no other equally difficult problem to overcome in a man's life than the birth of a handicapped child. No other event does cut your life so deeply, no pain is so unlimited by time. Death and parting can be overcome with time. Disability of a child has an opposite character – it is a constant presence and remains with the parents for their whole life"¹⁴.

Bibliography

1. Adamski F., *Socjologia małżeństwa i rodziny*, Warszawa 1984.
2. Franczyk A., Krajewska K., *Program psychostymulacji dzieci w wieku przedszkolnym z deficytami i zaburzeniami rozwoju*, Kraków 2005.
3. Goleman D., *Emotional Intelligence*, Media Rodzina, Poznań 1997.
4. Gunia G., *Pomoc i poradnictwo rodzinie dziecka z wadą słuchu* [in:] Dziecko z trudnościami w rozwoju, ed. S. Mihilewicz, Kraków 2005.
5. Kowalik S.: *Upośledzenie umysłowe. Teoria i praktyka rehabilitacji*, Warszawa – Poznań 1989.
5. Minczakiewicz E. M., *Wsparcie społeczne rodziny jako czynnik modelujący i kształtujący więzi w rodzinie wychowującej dziecko z głębszą niepełnosprawnością intelektualną* [in:] Roczniki Pedagogiki Specjalnej, Volume XII,XIII, ed. J.Głodkowska, Warszawa 2002.
6. Mrugalska K., *Rozdział III. Osoby z upośledzeniem umysłowym* [in:] Osoby upośledzone fizycznie lub umysłowo, ed. K. Mrugalska, Warszawa 1996.
7. *Psychologiczne i socjalne aspekty integracji dziecka niepełnosprawnego* [in:] Tematy, Pismo Pracowników Socjalnych, Terapeutów, Personelu pielęgniarskiego i opiekuńczego, no. 1, Kraków 1997.
8. Rembowski J. *Więzi uczuciowe w rodzinie*, Warszawa 1972.

¹⁴ Psychologiczne i socjalne aspekty integracji dziecka niepełnosprawnego [in:] Tematy, Pismo Pracowników Socjalnych, Terapeutów, Personelu pielęgniarskiego i opiekuńczego, no. 1, ISSN, Kraków 1997, p. 11.

9. Sekułowicz M., *Matki dzieci niepełnosprawnych wobec problemów życiowych*, [in:] Roczniki Pedagogiki Specjalnej, Volume XII,XIII, ed. J.Głodkowska, Warszawa 2002.
10. Tyska Z., *Socjologia rodziny*, Warszawa 1979.
11. Ziemska M., *Postawy rodzicielskie*, Warszawa 1979.

Summary

When a family functions correctly and a healthy child is born, all the psychological, emotional and social needs of its members are fulfilled. However in a family, in which an intellectually handicapped child is born, the family functions are disturbed and there occurs crises in its functioning. Such a family requires complex care and comprehensive support.