

Janusz Mastalski

Marginalization of families with a disabled child

The majority of scientists dealing with marginalization are of the opinion that social exclusion is not a state but a process, although there are doubts in this respect (Gordon et al. 2000).

Marginalization may be treated as a decrease in the importance of a given group in the society, due to, among others, a decrease in its number, weakening of its functions and position in the social hierarchy, having extreme views, or undertaking actions that are not accepted by the majority. It can also mean social exclusion of an individual. Social exclusion in this case may describe a process of an individual's exclusion or the state of being excluded. According to the Center for Analysis of Social Exclusion, an individual is socially excluded when: they are a member of a society from the geographical point of view, they cannot participate in normal activities of society members (due to reasons being outside their control), or they want to participate in the social activity but they are unable to (inability to participation in economic aspects of social life, inability to participate in political aspects of social life, inability to participate in cultural aspects of social life) (Barry 1998). The process of marginalization is pushing down an individual, group and even all societies into a situation of social disability by local or global economic and social processes, which results in depriving individuals of the ability of individual material functioning and condemning them to cultural isolation and confinement in a circle of barriers to independence and self-development, barriers which are difficult to overcome (Pilch 2004).

A disabled person may be a special example of a marginalization process. As a result of this marginalization, a family with a disabled person may yield to the so-called downward spiral, which is a special case of marginalization.

History of culture contains a lot of descriptions and rules for exclusion of some categories of people from a society. Detailed descriptions of this mechanism may be

found throughout history. Already in the Middle Ages, a disabled person was expelled from the world and Church community. In the modern times it has been more and more common to eliminate or intern people with psychological disorders or mal-adjusted ones. In the 17th century people called erring, and at that time this condition was placed in the hierarchy next to beggars, the homeless, tramps, misers, informers, convicts and all the others who disturbed 'the public order', were closed in hospitals, prisons and detention homes together with others who disturbed 'the order'.

The motives for a rejection are health, economic, political and religious ones. Together with social changes as well as medical progress, the emphasis was put on these or other motives, however, it is a mistake to believe that rejection, exclusion or open discrimination are only historical curiosities. A tendency to exclude can be observed also at present, in our society.

In the 18th century, the gauge of how humanity can be measured was applied for the first time – that was usefulness. In the 18th century the usefulness of a human meant first of all the ability to participate in the nascent capitalistic system of economy, so it had first of all an economic dimension (Foucault 2000). Neither the 19th nor the 20th century brought any improvement in this respect. It was M. Foucault who wrote many years ago:

'who is gaining now, thanks to the requirements of a capitalistic society, the status of an ill person, i.e. an individual who should be cured in order to restore them to usual work, meaning compulsory. This special modulation of capitalistic exclusion made it possible for a unique outline of a mentally ill person to be born, i.e. a madman who is not a madman since they are not afflicted with an illness. It is the same system that made it possible for a person who had never existed before to be born simultaneously or via a contact with a mentally ill – a psychiatrist.' (Foucault 2000: 98).

When talking about marginalization of a family with a disabled child, words of J. Vanier are also worth recalling:

'a disabled is neither a being who should be killed nor a being who is closer to God, gods or supernatural beings. It is a human being, however incomplete, having deficiencies, moronic, crippled, disabled. We, normal people 'without deficiencies' have no right to get rid of them (if sometimes we do not have the courage to do it physically, we unfortunately do it without hesitation in the spiritual and psychological sense, treating them rather like an object than a subject, a person). This is this 'poor thing' that should be helped and that should be protected. We treat them like children and they will be such children till the end of their lives. They should be given proper living conditions (...) first of all they should be offered some occupation, work, since they may turn out to be efficient!' (Vanier 1985: 161)

But, does an average citizen of the world understand this in the modern civilization? Thus, the basic dimensions of marginalization of the discussed families are worth presenting. They can be divided into three groups: stereotypes, toxic social attitudes and automarginalization.

Stereotypes

In the era of development of the mass media, such as a book, film, television, radio, press, advertisement, and of more and more common occurrence of the widely-understood disability in the media, a stereotypical perception or open discrimination of the disabled is a highly worrying fact. A stereotypical and false picture of the disabled present in the mass media results from superstitions and myths consolidated in the society for ages, which cannot be eradicated from people's consciousness. Wide access to the media and their great influence on the shaping of public opinion additionally strengthen these stereotypes, doing a lot of harm in the social perception of the disabled, as well as among the members of this group. A typical example of endorsing stereotypes is the so-called '*charity advertisement*,' where the disabled are presented as people in need, unable to exist on their own, pitiful. From such a picture it might be concluded that society is constantly obliged to charitable actions and donations that the disabled cannot manage without. As a consequence, the picture of people being a burden to the whole society, evoking pity, pushed into the background of social life is being consolidated. Such a way of presenting the problem of disability very negatively influences the social agreement, it increases the fear that disability is an experience destroying one's life. This increases social barriers, but also deprives the disabled of faith in their own abilities (Barnes 1992).

There is also a stereotypical conviction that an institutionalized solution separating work from life is the best for the disabled. Thus it is hidden violence in the form of a social consent for isolation (Sokołowska, Ostrowska 1983). Problems of contemporary work turn into potentially evoking conflicts since they exceed general declarations. It concerns especially the employment of the disabled who are at the same time entitled to a disability pension. In such a way the syndrome of a worse employee, a worse person is being created, which is already tinted with mental violence. There is a distance, growing larger and larger, that healthy people feel towards entering close or intimate relationships (e.g. friendship) with the disabled. This fear of being different is painfully felt by 'the differently abled' who often perceive such a behavior as aggression (Gustavsson, Zakrzewska-Manterys 1997). Moreover, lack of offices and schools adjusted to normal functioning of the disabled is also a form of a hidden stigmatization. Such people cannot be self-sufficient (Mastalski 2006).

It is also worth mentioning that the media often deal with cases of extraordinarily talented disabled people, emphasizing their great achievements, which is interesting for the wide audience. Such a presentation of disability has a number of negative consequences, e.g. misconception of their abilities results in reluctance to help them. It is also commonly thought that every blind person has a better developed sense of hearing or that a deaf person can correctly read the movement of the lips. In reality it is not so. Concentration of attention on the achievements of the disabled as individuals leads to a belief that they must deserve social acceptance in an unusual way (Barnes 1992).

Another stereotype, probably the most strongly rooted in the consciousness of healthy people, is connected with the opinion that a disabled person is helpless, left only to the mercy and care of somebody able. This opinion results from the belief that needs of the disabled are totally different from the ones of the healthy part of the society, and that their satisfaction is a heavy burden straining social means. Such a stereotype often leads to a hidden stigmatization of families with a disabled child.

Among the unemployed there are also disabled people who could successfully perform professional work, which is in fact a demand of a properly conducted rehabilitation process. A good preparation for work and employment provides people with e.g. personal and financial independence, however, for the disabled it has an additional value – it compensates for the limitations resulting from their disability. For this reason, a number of disabled people ascribe a lot of importance to work. It has a very high position in their hierarchy of values. Lack of work results in numerous attempts to gain it, e.g. searching for work via work agencies.

Toxic social attitudes

Another dimension of marginalization are social attitudes that in fact marginalize – in a hidden or sometimes open way – families willing to live in the sense of understanding and acceptance. There are six most often encountered toxic social attitudes.

1. *Distancing oneself.* It is an attitude consisting in avoidance of close and informal contacts with the disabled. Reluctance is expressed by the lack of emotional engagement in their problems. The family painfully feels this distance and simultaneously must protect itself against the feeling of inferiority.

2. *Devaluation.* It is a form of disseminating one's opinions of negative qualities of a defined group of disabled people (emphasizing negative features). It is a toxic attitude since it encourages untrue and harmful opinions about the disabled and their families. On hearing untrue opinions the family feels stigmatized.

3. *Delegitimization.* The situation where some legal articles make life of the disabled more difficult (e.g. issues connected with attending a 'normal' school or with employment). The main reason why companies do not want to employ the disabled are frequently changing and complex legal regulations of the duties of employers. Another reason is the fear of the costs of work-place adjustment. Moreover, employers are also afraid that a disabled person may suddenly fall ill and require additional help – so such a person is unstable for a company.

4. *Segregation.* This attitude consists in isolation of a disabled person from a given group or even the whole environment (Kowalik 1999). Some maintain that the process of integration is expensive whereas the disabled do not contribute much to the economy. Moreover, diversity make things weaker and only uniform groups

are really effective in their actions – the ones belonging to the same kind, sharing generic features, homogeneous (Bogucka, Kościelska 1996).

5. *Prejudices*. It is an attitude repeatedly stigmatized with the fear of the disabled and thus stigmatized with stereotypes (Greenwald, Banaji 1995). So it is all about acceptance, however with a long distance, under the influence of simplified opinions on disability. Research conducted in the recent years in our country points to a considerable diversification of attitudes towards the disabled in the Polish society. There are still people presenting a determined negative, isolating attitude. These people have a very limited knowledge about the disabled. In their opinion, such persons have numerous limitations in their physical and mental fitness. People presenting a negative attitude avoid contacts with the disabled and their families. They are usually afraid that they will not be able to behave properly in the contacts with the disabled and that they may experience unpleasant situations. Such people do not let their children play with a disabled child. Sometimes they ostentatiously show pity and compassion (Krasiejko 2001).

6. *Hidden marginalization*. Disability is often listed (next to crime, economic or cultural degradation) as a reason for social marginalization (Ostrowska, Sikorska 1996). It should be remembered that adjustment to a life with disability, regaining and maintaining a balance is a very difficult task, however, it is possible to manage on one's own, though with a bit of help on the part of others. People who have accepted their disability will aim at satisfying their needs, at mental and social adjustment, and at further self-development. It is of course possible, on the condition that social marginalization (e.g. indifferent attitude) is a rare and marginal phenomenon.

Talking about toxic social attitudes towards the disabled and their families, the following words of J. Wyczesany are worth quoting: 'Our schools are also not adjusted to shape pro-integrational attitudes of children and youth towards disability and the disabled. There is no separate school subject covering upbringing in tolerance, and within obligatory subjects topics explaining disability issues have not been included. Simultaneously, the youth at school often hear from the teacher: 'you blockhead, you're fit for a special school', 'you must be deaf', etc. In the subconsciousness of a young person, the opinion that 'those' are a category of worse people and less useful in the society is being consolidated. In the educational layer, the most important is dissemination of rational knowledge about otherness with simultaneous elimination of prejudices and stereotypes based on irrational reasons. This requires, among others, improvement of the school curricula, but it does not necessarily mean introducing new subjects' (Wyczesany 2002: 31). As can be seen also educational units may contribute to marginalization of the disabled and their families. This in turn may lead to the so-called automarginalization that is worth discussing in more detail.

Automarginalization

Unfortunately, in Poland we still observe the process of a self-driven social isolationism, having its basis also in the disabled themselves, who are used to playing the role of people excluded from the society. The situation of stigmatization and otherness of mentally disabled people and, most commonly, with smaller adaptation abilities puts these individuals in an especially difficult situation. Their dependence on other people is usually greater, which results in creation of unfavorable situations of a different character – such as: overprotectiveness, lack of autonomy, rejection, isolation, automarginalization (Zawiślak 2002: 95). So what are the signs of automarginalization of the disabled and their families?

First of all one must admit that not once do parents of the disabled children fear social reluctance and aggressive curiosity (Borzyszkowska 1997). This situation is connected with psychological pain and caring for the ill person. Its consequence may be escape and closure (Price 1988). It must be remembered that self-stigmatization as an adjusting mechanism concerns not only the ill but also, or maybe first of all their family environment. In the social consciousness there is a fairly deeply rooted conviction that healthy people are not willing to socialize with mentally disabled people (Leszkowicz-Baczyńska 2001).

Another sign of automarginalization is overprotectiveness of parents. There are often situations where parents want to compensate the child for its suffering. For example, after difficult rehabilitation exercises during which the parent may seem to be an aggressor, the mother tries to “make up for love” and pampers the child. Setting no limits, she teaches the child a chaotic world without the sense of safety. In such a way, the family turns into a kind of ghetto. Only at family home do the members of a family find safety, while the outer world is treated as an abyss of violence, lack of understanding and suffering.

Another equally dangerous dimension of automarginalization is hidden aggression on the part of siblings. A family situation often leads to neglecting the healthy children or burdening them with tasks exceeding their strength. Healthy children bear severe consequences of being brought up in a family where there is a disabled child. They are omitted and neglected; they often helplessly look for support (Kubiak 2003). As a result of this process, automarginalization of the whole family takes place, but there is also automarginalization of its members. The atmosphere in such a family is very tense and the parents feel more and more incomprehended by each other, as well as by the whole outer environment.

Undoubtedly, another sign of automarginalization is the way of making decisions in families with a disabled person. As an example one may present the conclusions from a research conducted among moderately disabled people. Thus adults who are moderately mentally disabled differ with respect to decisive competences from mentally abled people. They are not able to make independent decisions in the same scope as healthy people. They also do not participate to a comparable

extent in family collective decisions as their healthy peers do. Large differences among individuals let us deduce that this fact cannot always be explained by limitations resulting from mental disability. No less significance should be ascribed to negative, self-reliance-limiting attitudes of family surroundings towards the disabled (Zawiślak 2000).

Beside many other signs of automarginalization one more is worth mentioning – the one connected with sexuality of the disabled. Sexuality of the disabled is becoming uncomfortable for many and that is why it may be a cause of violence. Society at present tends to accept the disabled, however, without the right to show sexual interests (Molicka 1994). There are two aspects of this issue. The former can be called sexuality that is ignored by society, and even by the parents, who often curb strengthening of sexual identity of disabled children (Harwas-Napierała 1998). There are various actions trying to prove that these people are asexual. Moreover, by dressing these children in a way making them unattractive, and by making their adolescence look infantile ('but it's only a child') parents apply a special kind of violence. Such violence consists in depriving the disabled of the right to experience their sexuality. The latter is a frustrated sexuality. This is a social attitude where procreation of the disabled is prevented, which in turn is connected with the picture of genetic carrying of disability features, as well as a social idea of upbringing inefficiency of the disabled. However, these regularities have not been supported scientifically (Kościelska 2004). In Poland, sexual needs of the mentally disabled are rarely openly discussed and written about. Even more rarely one talks with these people about sexuality. It is believed that talks about 'these things' can only unnecessarily arise their interest in sex. Parents, teachers, class tutors and curators are all afraid of talking to them about this subject. Intellectually disabled people are often left alone with their sexuality problems (Stanisławski 2004).

It is also worth mentioning that a sick child 'makes' the family redefine and modify the objectives of their life's activities. Some parents think that for the good of the child they must sacrifice themselves, give up a better-paid work or give up work at all, give up all pleasures, social contacts, outings, etc (Radochoński 1987). The consequence may also be the process of gradual automarginalization.

From the above, it may be concluded that the process of marginalization of families with disabled family members is not so rarely encountered. That is why at the end it is reasonable to formulate a few demands referring to the actions preventing and minimizing marginalization of such families. These are as follows:

1. Tolerance seems to be a *sine qua non* condition of integration as such. Tolerance is the first step in the process of abandoning an uncivilized attitude, as it makes it possible for the people so far rejected 'to be right beside'.

2. The second important element of counteracting the discussed marginalization is upbringing to a dialogue. It is not only the carrier of some values but it is itself a value to which one should be brought up. A dialogue with a family living in one home with a disabled person is opening space for this family in the world.

3. Another element integrating a family with a disabled person is solidarity that covers brotherhood and humanitarianism, and love to one's neighbor (Grzybowska 1997). The disabled must be aware of the fact that they are not alone in their otherness. The sense of acceptance is an important element of identity and proper self-evaluation.

4. It should also be taken care of that the whole upbringing and therapeutical process should make it easier for the disabled – whether intellectually or physically – to exist in social life. They are to be accepted, become self-reliant and integrate as much as possible.

5. An important part is played by these people who can stand beside a family with a disabled person – whether friends, doctors or social curators. Parents should be encouraged to try to face an undoubtedly difficult situation without closing themselves to others.

6. Aspiration to love presented by the mentally disabled has its sources in the emotional sphere and cannot be associated with an emotional impulse or only arousal. Desire for personal contacts, friendship and partnership closely connected with faithfulness is not alien to them. That is why taking care of their emotional development is worth encouraging, as well as making their parents aware of the sexual and emotional needs of disabled children (Mastalski 2006).

Many people afflicted with a serious illness consider themselves to be worse, useless, unable to gain anything on their own or to win. The society must grow up to the view of the disabled. And the disabled, despite impediments, should not close nor be closed by their parents. Marginalization of the disabled as well as their families should become a priority in the process of helping people afflicted with different disabilities. It must be remembered that the disabled are a living picture of a real man, they embody personal dignity. The disabled have a possibility of a more efficient personal development. In a disability spiritual – personal powers are more toughened up. The picture of a disabled person is a challenge for the 'abled'. Being aware of these truths is the beginning of counteracting marginalization of 'the differently abled'.

References

- Barnes C. (1992). *Disabling Imagery and the Media: An Exploration of the Principles for Media Representation of Disabled People*. Derby.
- Barry B. (1998). *Social Exclusion, Social Isolation and the Distribution of Income*. London.
- Bogucka J., Kościelska M. (1996). *Wychowanie i nauczanie integracyjne. Nowe doświadczenia*. Warsaw.
- Borzyszkowska, H. (1997). *Izolacja społeczna rodzin mających dziecko z upośledzeniem umysłowym lekkim*. Gdańsk.

- Foucault M. (2000). *Szaleństwo i społeczeństwo*. [In:] M. Foucault. *Filozofia, historia, polityka. Wybór pism*. Warszawa – Wrocław.
- Foucault M. (2000). *Choroba umysłowa, a psychologia*. Warszawa.
- Gordon D., Adelman L., Ashworth K., Bradshaw J., Levitas R., Middleton S., Pantazis C., Patsios D., Payne S., Townsend, Williams J. (2000). *Poverty and Social Exclusion in Britain*. York.
- Greenwald A.G., Banaji M.R. (1995). *Implicit Social Cognition: Attitudes, Self-esteem and Stereotypes*. *Psychological Reviews*, 102.
- Grzybowska D. (1997). *Wychowanie w i do integracji z niepełnosprawnymi*, *Edukacja i Dialog*, 9.
- Gustavsson A., Zakrzewska-Manterys E. (ed.), (1997). *Upośledzenie w społecznym zwierciadle*. Warsaw.
- Harwas-Napierała B. (1998). *Niektóre uwarunkowania i zagrożenia rozwoju tożsamości płciowej dzieci*. *Forum Psychologiczne*, 3.
- Kościelska M. (2004). *Niechciana seksualność*. Warsaw.
- Kowalik S. (1999). *Psychospołeczne podstawy rehabilitacji osób niepełnosprawnych*. Katowice.
- Krasiejko I. (2001). *Tolerancja wobec niepełnosprawnych*. *Edukacja i Dialog*, 8.
- Kubiak K. (2003). *Niepełnosprawność – źródło przemocy czy sił?* *Edukacja i Dialog*, 4.
- Leszkowicz-Baczyńska Ż. (2001). *Samostygmatyzacja jako mechanizm przystosowania społecznego*. *Nasze Forum*, 3–4.
- Mastalski J. (2006). *Chrześcijanin wobec przemocy w rodzinie*. Kraków.
- Molicka M. (1994). *Rozwój psychoseksualny upośledzonych umysłowo w świetle literatury i rozważań własnych*. *Szkoła Specjalna*, 3.
- Ostrowska A., Sikorska J. (1996). *Syndrom niepełnosprawności w Polsce. Bariery integracji*. Warsaw.
- Pilch T. (2004). *Marginalizacja społeczna a edukacja*. [W:] *Encyklopedia pedagogiczna XXI wieku*. Warszawa.
- Price D.D. (1988). *Psychological and Neural Mechanism of Pain*. New York.
- Radochoński M. (1987). *Choroba a rodzina*. Rzeszów.
- Sokołowska M., Ostrowska A. (1983). *Socjologia kalectwa i rehabilitacji*. Wrocław.
- Stanisławski P. (2004). *Seks upośledzany*. *Integracja*, 4.
- Vanier J. (1985). *Wspólnota*. Kraków.
- Wyczesany J. (2002). *Wartości jako źródło poglądów młodzieży na temat osób niepełnosprawnych*. *Konspekt*, 10.
- Zawiślak A. (2000). *Udział osób upośledzonych umysłowo w stopniu lekkim w podejmowaniu decyzji rodzinnych*. [In:] R. Derbis (ed.). *Jakość rozwoju a jakość życia*. Częstochowa – Warszawa.
- Zawiślak A. (2002). *Społeczne wsparcie osób upośledzonych umysłowo w stopniu lekkim*. [In:] A. Pielecki (ed.). *Problemy pedagogiki specjalnej w okresie przemian społecznych*. Lublin.

Marginalizacja rodzin z dziećmi niepełnosprawnymi

Streszczenie

Większość naukowców zajmujących się marginalizacją uważa, iż wykluczenie społeczne nie jest stanem, lecz procesem. Proces marginalizacji jest spychaniem jednostek, grup, a nawet całych społeczności w sytuację upośledzenia społecznego przez lokalne lub globalne procesy ekonomiczno-społeczne, w efekcie których zostają one pozbawione możliwości samodzielnego funkcjonowania materialnego, a także są skazane na izolację kulturową i zamknięcie w kręgu trudno przezwyciężonych barier do samodzielności i samorozwoju. Szczególnym przypadkiem procesu marginalizacji może być osoba upośledzona. Natomiast rodzina z osobą upośledzoną wskutek owej marginalizacji może ulec tzw. spirali upadku, czyli właśnie szczególnemu rodzajowi marginalizacji. Podstawowe wymiary marginalizacji owych rodzin można podzielić na: stereotypy, toksyczne postawy społeczne oraz automarginalizację. Marginalizacja osób upośledzonych, jak i ich rodzin powinna stać się priorytetem w procesie wspomagania ludzi dotkniętych różnego rodzaju niesprawnością. Obraz człowieka niepełnosprawnego stanowi więc wyzwanie dla „sprawnych”. Uświadomienie sobie tych prawd staje się początkiem przeciwdziałania marginalizacji osób „sprawnych inaczej”.