

CZĘŚĆ I: ROZPRAWY I ARTYKUŁY

PREVENTING SOCIAL EXCLUSION OF PEOPLE WITH DISABILITIES
AND THEIR FAMILIESWALKA Z WYKLUCZENIEM SPOŁECZNYM OSÓB NIEPEŁNSPRAWNYCH
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Kornas-Biela D., Domagała-Zyśk E., Smółka E. (2016), *Preventing social exclusion of people with disabilities and their families*. Rozprawy Społeczne, 1 (10), s. 7-15.

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Summary

In the light of the contemporary biopsychosocial model of disability, social exclusion is not an individual problem of the individual, but the situation significantly altering the functioning of the entire family system. Disability can be a cause of social exclusion for both the persons with disability and their families. Therefore, it is important to look for effective (formal and informal, institutional and non-institutional) ways to support families with disabled persons particularly in those activities that enhance the quality of life of families affected by disability. The purpose of this article is to show the importance of social support and examples of good practice that prevent social exclusion of both the persons with disabilities and their careers.

Keywords: social exclusion, model of disability, family, intellectual disability, hospice

Streszczenie

W świetle współczesnego biopsychospołecznego modelu niepełnosprawności wykluczenie społeczne nie jest indywidualnym problemem jednostek lecz sytuacją, która w dużym stopniu wpływa na funkcjonowanie całego systemu rodzinnego. Niepełnosprawność bywa przyczyną wykluczenia społecznego zarówno w odniesieniu do samych osób niepełnosprawnych, jak i dla ich rodzin. Dlatego ważne jest znalezienie skutecznych (formalnych i nieformalnych a także nie-instytucjonalnych) sposobów wsparcia rodzin osób niepełnosprawnych, w szczególności w odniesieniu do działań, które podnoszą jakość życia rodzin dotkniętych niepełnosprawnością. Celem tego artykułu jest wskazanie dużego znaczenia wsparcia społecznego oraz przykładów dobrych praktyk, które zapobiegają wykluczeniu społecznemu zarówno osób niepełnosprawnych jak i ich dróg kariery.

Słowa kluczowe: wykluczenie społeczne, model niepełnosprawności, rodzina, niepełnosprawność umysłowa, hospicjum

Tabele: 0

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Otrzymano: 09.10.2015

Zaakceptowano: 06.11.2015

Introduction

In the light of the contemporary biopsychosocial model of disability, social exclusion is not an individual problem of the individual, but the situation significantly altering the functioning of the entire family system. First of all, disability can be a cause of economic and social exclusion of both the persons with disability and their families. Consequently, today it is of utmost importance not only to know the disabled persons needs, but to look for effective (formal and informal, institutional and non-institutional) ways to support them thus enhancing their social inclusion.

The purpose of this article is to show the importance of social support and examples of good practice that prevent social exclusion of both the persons with disabilities and their careers. It starts with presenting the anthropological and philosophical perspective on disability which perceives this state not only as a difficult life situation but as a source of development and growth. Then three different models of disability are described and analysed. In the third part of the paper, we present the situation of a family with a disabled member in the context of social exclusion. As a way of preventing this exclusion we see different initiatives of state, church and non-

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governmental organizations in Poland which aim at addressing this issue in a systematic and holistic way, enriched with spiritual dimension. Activities undertaken by these organizations can serve as good practices of supporting the disabled persons and their families and enabling their social inclusion.

A disabled person in the anthropological-philosophical aspect

Before we present various forms of supporting the social integration of disabled persons, it is worth discussing the philosophical-anthropological interpretation of the fact and experience of disability, as well as the position of the disabled in the community. According to the legal definition, disability is "a constant or temporary incapacity to perform social roles due to a permanent or long-term impairment of the organism, especially one causing inability to work¹." Therefore, the category of disability is related to a certain deficiency in the physical, psychological or intellectual sphere which prevents one from performing their social roles, and especially, as the definition states, limits the prospect of undertaking full professional activity or makes it altogether impossible. Thus, disability is defined in the light of incapacity to work, dependence on other people in the material sphere, impossibility to fulfil one's obligations to the society. Therefore, a person is defined through the prism of functions one has to perform in the society, while a disabled person – through the prism of limitations in fulfilling this function. Such a view may lead to reductionism, linking a person's value to his or her productivity and social utility. Consequently, a disabled person might be assessed as less valuable.

On the other hand, the above presented definition indirectly highlights the role of the social context in a person's development. Disability is a deficiency which can interfere with one's integration with the society and limit a given person in performing not only professional roles, but also, in a broader context, social roles connected with the participation in a family, environmental, religious or national community.

In order to take care of a full integration of the disabled, a more thorough examination of the way disability is defined is needed. In the philosophical aspect, disability is related to the category of contingency, with existential non-self-sufficiency, fragility, deficiency, which affect every person, though to a different extent. Deficiencies may concern the physical, intellectual, volitional or emotional sphere. They may be more or less noticeable and limit the development of a person to a smaller or greater extent. Often the situation of people who, according to the definition are disabled, is not much different from that of the so-called "able-bodied" or "non-disabled" – a person in a wheelchair may feel fulfilled with respect to professional work and family, and therefore

he or she does not expect special attention from the society. And conversely, a completely healthy person endowed with many talents may waste them lacking consequence, determination and what we term the strength of character. Contingency is therefore a mark of every person; it is at the same time a challenge and a task. It equally concerns the able-bodied and people with disabilities.

The first and the most basic dimension of a human is the dimension of being a person. It is the specific core of humanity, hidden under the multitude of appearances and personalities – people's talents, abilities, but also deficiencies and disabilities. It is this dimension that connects a disabled person with other people. The vocation of a human is in this dimension a vocation for realizing the personal human nature during one's life. Just like other people, a disabled person is meant to improve himself or herself – and through it, the surrounding world and other people – through realizing such values as: truth, moral good, love, beauty; through actively participating in strictly human domains of being such as the family, work and society (Chudy 1988a, p. 148). Supporting a disabled person in his or her development, finding an adequate form of this help requires defining the essence of humanity. Attempting to describe this rudimentary dimension of being a person, Chudy states that it is determined by the ability to rationally and reflectively devote oneself to the highest values, especially the ability to feel love defined as an unselfish gift of oneself (1988a, 125). There can be distinguished a few fundamental features of a human being. They will be analyzed below.

A human is a rational being; humans learn about themselves and the world that surrounds them. They are also conscious of this fact; thanks to reflection they are able to follow the course of their own cognitive process. They witness their own experiences and feelings. One's contingency, disability is also a piece of data available for experiencing and reflection. The reflective dimension of a person allows one to feel a certain distance from who one currently is. Spaemann (2001) states that people do not equal their nature; disability, as long as it does not concern the mental sphere, does not determine a person. It is worth referring to the life testimony of Nick Vujicic, who suffers from phocomelia, a rare condition involving the lack of limbs. In spite of his disability, Vujicic leads an active professional life: he is a motivational speaker and runs business, training and coaching people all over the world. He is a fulfilled husband and father. The title of the Polish edition of his autobiography is symptomatic: *No arms, no legs, no limits!*

A person is free – he or she makes independent decisions based on the recognized truth. Human freedom is not unlimited – the above mentioned Nick Vujicic cannot undertake many activities available for people with all limbs. W. Chudy, a professor of the John Paul II Catholic University of Lublin, bound all his life to a wheelchair, wrote: "A life concentrated on the narrow scope of possible human perception

1 Ustawa z dnia 27 sierpnia 1997 r. o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych (Dz. U. z 2011 r. Nr 127, poz. 721, z późn. zm.) <http://www.niepelnospawni.gov.pl/prawo-/dzu2012-poz-986/>

and activity [limited by disability – my addition – E.S.] becomes cognitively and emotionally focused, as a result predisposing a person to a contemplative attitude and prevents his or her feelings and vital energy from dispersing into pseudo-values” (1988a, p. 133). Disability is not necessarily linked to “a reduction of the personal character of human life, neither does it have to determine a distortion of the development of a human being. On the contrary, if it is appropriately faced and affirmed, it can constitute a valuable form of realizing personal life of the disabled as well as of their overcoming the evil brought by the disease and suffering” (Chudy 1988a, p. 133).

A person is open to the community – striving to establish relationships with other people does not result from expecting greater benefits which are brought about by such cooperation. The most valuable relationships are based on disinterestedness. Paradoxically, a person realizes himself or herself best through a selfless gift of oneself. The ability to perform an act of disinterested kindness is the fundamental act of the person. For many personalists (J. Maritain, K. Wojtyła, R. Spaemann), such an act marks the beginning of a life befitting a person, as it requires overcoming the concentration on the self, natural for the human – on one’s perception, needs, talents and deficiencies. For the disabled, it is a chance for overcoming the perspective of perceiving themselves through the prism of their disability, a sense of injustice, demands. It is the openness to the question: what can I give to other people thanks to my disability (or in spite of it)? Meeting a disabled person is also a chance for the people who accompany them – families, carers, the society. The attitude to the disabled is a test of humanity. It is often also a testimony of everyday heroism of the persons taking care of their disabled relatives, giving up professional activity in order to provide them with the optimal level of care and development. Such an attitude is a manifestation of disinterestedness, a gift of the self without calculating gains and losses – the essence of humanity. The effort of overcoming egoism and every selfless gesture reveal the ability to love inherent in a person’s nature, and in this meaning the disabled give more than they receive. In 1984 in Quebec, John Paul II said: “Unquestionably, the quality of a society or civilization is measured by the respect it has for its weakest members” (as cited in Chudy 1988, p. 134). Therefore, an extremely important social task is the help and support for the families of the disabled, so that they do not have to rely solely on their limited possibilities and strength.

A person is a body. Corporeality is an integral element of being a person, as important as rationality, freedom, openness to other people. A person expresses himself or herself and communicates through the body; there is no other possibility. Therefore, a disability, the limitations of certain functions, above all disrupt human communication and contact with the world in general. Mental, hearing, vision, speech or mobility disorders hinder getting to know someone, exchanging information or expressing emotions. They interfere

with what the essence of a person is, his or her need for establishing interpersonal relationships. They hinder it, but do not make it impossible. A lot depends on sensitivity, concern, openness of the people who accompany the disabled. Therefore, aiding their development and showing concern for improving their impaired functions serve as support for communication.

Dignity as an inviolable value of a person is the least tangible feature. A human is a person throughout his or her whole life, irrespective of his or her health, intellectual or social condition. A disability concerning somebody’s physical or psychological sphere, or even limiting the functions of his or her mind, does not affect the human spirit, cannot violate or disrupt the personal structure of the human. Even people with profound mental retardation, with whom we cannot establish mutual verbal communication, do not cease to be persons. In a natural way, we perceive them as persons – sick, dependent and therefore needing help. Spaemann (2001) claims that in the relationship with these people it is revealed in a special way if we have the proper knowledge of what it means to be a person. “Their existence is the acid test of our humanity. [...] They evoke the best in human beings; they evoke the true ground of human self-respect. So what they give to humanity in this way by the demands they make upon it is more than what they receive” (p. 300). Such a test consists of affirming a person not for his or her attractiveness, but in spite of the lack of such attractiveness. It can be said that it is a peculiar skill of perceiving a person’s dignity and his or her morally binding character.

Affirmation of a person’s dignity is, according to Wojtyła (1982), “a mature involvement of the will with another person, with his or her good in view” (p. 85). This short definition of love establishes a manner of persons’ attitude towards each other. The good of a person requires taking into consideration the limitations and possibilities of a specific person. It is especially related to people with different forms of disabilities – the concern for their development should be motivated by their individual good and potential. It might present difficulties for the parents and relatives, for whom it is not easy to give up the image and the expectations they used to have of the child.

Medical, social and psychosocial models of disability

In the first chapter we presented anthropological and philosophical picture of a person with a disability. It was confirmed that each person, despite different deficits, handicaps and illnesses, can be described as possessing full human rights and dignity of a human being. Acknowledging this, each person should be approached with an attitude of love (Wojtyła 1982, p. 85), which can take a form of acceptance, support, help, tolerance or kindness. Unfortunately, it is not the case in many parts of the world and the disabled person can be confronted with different attitudes. Individual attitudes towards persons with disabilities are shaped by social attitudes which can be named as

models of disability. There are three models of disability which are commonly recognized: medical, social and psychosocial.

Traditionally, the medical model prevailed: disability was treated mainly as a bad medical condition: *disorder, deficit, illness or handicap* and a common attitude to it was to “repair”, change into “normality” by medical treatment or therapy. The ultimate aim of many activities was to adjust a disabled person to life in open society and only professionals were regarded as those who know how to do this. A disabled person was a passive receiver of services aimed at cure or management, which were usually given in institutions enforcing isolation: hospitals, special schools, special workshops and orphanages. In scientific studies a main model of research was comparative in its character: the levels of significant physical, psychological and social differences between disabled and non-disabled persons were estimated which usually meant that the disabled were presented as less skilled, independent, intelligent etc.

The social model of disability was proposed by Mike Olivier in 1983 (cf. Barnes 2003, p. 5). In this approach it is the physical, social and cultural environment that is perceived as a source of different handicaps connected with disability. Common examples of such handicapping structures are (Rieser 2008): inaccessible environment, lack of useful education, discrimination in employment, segregated services, poverty, “belief” in the medical model of disability, inaccessible information and transport, prejudice and de-valuing. The psycho-social model has been described and promoted by, e.g. Kirenko (2005, p. 67). He states that the social model of disability in a way takes the whole responsibility for the disability from the person and places it within the environment. According to Kirenko, the disabled persons themselves are in many cases partly responsible for their disability (e.g. due to risky behavior leading to an accident). Disabled persons should also try to become a part of the society and adjust, if possible, to its rules. It is not only the environment that has to be adjusted, they are also the disabled persons themselves who should undertake this effort.

Social and psycho-social models of disability call for various social actions aimed at changing the situation of disabled persons. These activities are directed mainly at overcoming the barriers which make it difficult for the disabled persons to participate in education as well as social and professional life. Physical environment is becoming more and more accessible thanks to adjusting streets, pavements and buildings to the needs of the motor and visually disabled persons: the stairs are accompanied by ramps, pavements have curbs changed into bumpy surfaces, stairs into lifts and escalators and buildings are accessible thanks to automatic doors. Accessibility is also important for hearing impaired citizens and it can be reached by overcoming the communication barrier thanks to sign language interpreters and

sign language usage in institutions², subtitles and services such as speech-to-text reporting for hard-of-hearing persons. Legal barriers can be overcome by numerous changes of parliament acts and other documents. A great support in this work comes from the UN Convention on the Rights of Persons with Disabilities, signed by UN in 2006. The most important barriers seem to be, however, the mental barriers and stereotypes about disability that make it difficult for disabled persons to participate fully in social life. A lot of work has to be done to change negative and exclusive social attitudes so as to achieve full social integration and inclusion of persons with disabilities as proposed by the social model of disability. This change of social attitudes should start from the most important environment – a family.

A person with a disability in the family

When one of the family members is disabled, the whole family system is affected by this fact and endangered by social exclusion. That is why it is so important to analyze the situation of such a family, understand the challenges it has to meet and offer solutions that can support social inclusion of these families. A family that has a member with a disability faces challenges from the first moments of receiving an unfavourable diagnosis or noticing the first worrying symptoms of disability. Until not long ago, these challenges used to refer to the period after birth, but at present, as a result of the developments in prenatal diagnostics, many developmental problems are diagnosed before birth. The appearance of a child with developmental problems makes all family members face various difficult experiences for many years, and often parents suffer until the end of their lives. Their power, intensity and scope differs among the members of the same family, but the content and depth of these experiences is significant for the personal life of each individual member, for their mutual relations and for their attitudes towards the child with a disability. Each family as a whole, and all family members, have their own, specific experiences and modes of functioning concerning the person with a disability present among them. Many publications stress that the presence of a person with a disability in the family affects its structure, has a negative impact on its members' sexual-procreation functioning, the material-economic functioning, the service-caregiving functioning, as well as the educational, social and psycho-hygienic functioning of the family (Twardowski 1999).

Traditionally, for the sake of description and understanding of parents' experiences, one can differentiate some commonly occurring stages of adaptation to the disability in the family. The parents' experiences and reactions differ depending on the stage of adaptation: first, the period of shock, then, negation, after that guilt and shame, next, grief,

² Poland and many other countries have the Sign Language Act (2011) which recognize sign language as a first and basic language of some citizens and requires sign language usage in education, work and social life.

anger and finally adaptation (Kornas-Biela 2001b). Meanwhile, a child with a disability, as any other child, grows, develops and becomes an adult. Until recently, the focus of psychologists, educators and teachers has solely concerned the child. However presently, the person with a disability lives the majority of his or her life as an adult. "Early intervention" is no more sufficient in the youth period and then in the adult life. New problems arise with regard to fulfilling one's dreams and interests, sexuality, wishes about one's own family, children, finding and keeping a job or having friends. The issue concerning the persons with a disability who are getting older in the family, or those whose parents are getting older and worried, has not yet been effectively addressed by special education and social services.

Having a child/person with a disability in the family is a great challenge for the functioning of the whole family system. Each member has more duties related to fulfilling the material, educational, hygienic, therapeutic and social needs of the person with a disability. This constant "binding", and the "inability to escape the situation" is an emotional burden. The remaining family members, especially parents, restrict their social contacts and have no time to take care of their own health, therapy, hygiene, relaxation or vacation. Frequently, one of them must resign from their job, which firstly means limiting their personal and professional development, the opportunities for education and raising their qualifications. Secondly, it means reducing the family's financial resources, and thus limiting the possibility of an effective therapy and satisfying the needs of all the family members (Kornas-Biela 1988). That is why families with a person with a disability more frequently face such difficulties as financial problems (costly therapy, education, care, travel to medical centres for examinations, etc.), limited functional activity in social-cultural life (lack of time, funds and organisational conditions to use cultural and social facilities, vacation, travel), limited care and control over the child's siblings, difficulties in satisfying the needs of the aging grandparents and various other deficiencies in the everyday existence.

The family members of a person with a disability may also experience symptoms of burnout, similar to professionals with burnout syndrome. They are overloaded with duties, they often do not see evident results of their efforts and time spent with the child, and they cannot regain strength through rest, leisure and taking care of themselves – which altogether leads to a long-term overload of the organism, chronic fatigue, apathy, a sense of uselessness, ineffectuality and helplessness. The numerous monotonous everyday activities and difficult therapeutic exercises make them behave automatically, and they become tired and bored. Parental burnout affects the whole family and causes various difficult or even dangerous situations, e.g. it disturbs rational thinking, destroys emotional bonds, leads to depression (even of all family members), breakdowns in the family or even suicidal attempts. The family members are overwhelmed

and discouraged. They lose faith in the effects of any therapy, and do not have the internal strength to seek specialist help that would require their involvement.

There are various stereotypes and superstitions about persons with a disability and their families in the society. Hence, these persons are frequently rejected, isolated, mocked, disregarded or humiliated. The discrimination may take different forms and degrees – from distancing (avoiding, not getting involved), devaluation (stressing one's beliefs about the negative features of persons with a disability) and delegitimation (strengthening negative evaluations in the form of habits and legal regulations) to segregation (limited access to the whole environment, isolation) and extermination (taking the life of persons with a health or developmental problem before their term birth in selective abortion after an unfavourable diagnosis, euthanasia of terminally ill persons) (Kowalik 1996, p. 162-164). The social situation of the family is one of the factors that contributes to the isolation or integration of its members in the society. The attitudes of the environment are crucial for the acceptance of disability and adaptation to it, as well as for a successful therapy process. These social attitudes may support and facilitate this process, or on the contrary, they may hinder or block it, and changing these attitudes may be more difficult than overcoming the immediate results of the physical or mental disability. Social attitudes also play the role of self-fulfilling prophecies, and if they are negative, they limit the possibility of satisfactory social contacts, cause various problem situations (Kornas-Biela 2006) and lead to a psychological and social degradation of disabled persons and their families, and to their even deeper dysfunction (secondary disability – see Kowalik 1996, p. 172-173), which in turn makes the social attitudes less favourable towards these persons, as in a vicious circle. However, many families have overcome the pain about their member's disability. Moreover, they experience love and joy in contact with this person and altogether cope with the situation well, but the society expects them to have an attitude of sorrow, grief and giving up their needs, leisure activities, interests or social involvement.

It is prejudice, superstitions and negative stereotypes in the society that stigmatise persons with a disability and their family members and hinder their adaptation to the situation. Social stigmatisation is especially difficult to overcome if they were exposed to such social beliefs before the disability appeared in their family. This is why initially family members must cope with the prejudice in themselves as it disturbs their relations with the child, others and themselves.

Struggling with the deprivation of their emotional needs, the difficulties of everyday life, caring for a person with a disability, problems in marital relations, negative social opinions, etc., family members themselves sometimes accept the unfavourable beliefs and attitudes to the person with a disability, such as overt or covert rejection or indifference, and commonly have excessive expectations, a tendency

to control or provide excessive care and protection of the person with a disability (Maciarz 1984, p. 43-47). This is accompanied by negative attitudes towards the environment, such as a demanding attitude, attitude of the so-called learned helplessness, and isolation.

The disability of a family member affects the dynamics of marital life and the mutual bonds between the parents, the child with a disability and the siblings, and this impact keeps changing as the child grows, develops given personality traits, emotional contact, abilities, talents and problems. Parents and siblings try out many ways of adjusting to the situation, coping with stress and satisfying their psychological needs, seek various forms of support. Their adaptation to the disability of a family member is a life-long, dynamic process, affected by various factors.

Many families, however, view the appearance of a child with a disability or disease altogether as a blessing – or at least not as a tragedy destroying the family. However, little is known about the emotional consolidation and potential revival of the family when disability appears. We pay little attention to the value and the untouchable dignity of the person with a disability (Kornas-Biela 1999, 2001a) and to the positive aspects of its presence in the family and the human community as such (Vanier 1999, 2006, 2010, 2011).

Examples of good practices in Poland

In this part of our paper we would like to present five examples of “good practices” in the field of supporting social inclusion of persons and families with a disability problem. Both examples of all-Poland institutions and solutions as well as initiatives from the Lublin local environment are presented. The following examples are discussed: 1. Little Prince Hospice for Children; 2. The Polish Association for the Persons with Mental Disability, an all-Poland association offering support for the intellectually disabled children, teenagers and adults; 3. A State Group Home in Lublin – institutions providing accommodation for intellectually disabled adult persons; 4. L’Arche family-like homes for intellectually disabled persons. All these institutions are characterized in next few paragraphs.

The Little Prince Hospice in Lublin

An especially valuable initiative for the benefit of the youngest persons with a disability and their families is the activity of perinatal hospices. One of the threats of the extermination of human life at its very beginning is an unfavourable prenatal diagnosis concerning the child’s health. After getting dramatic news, i.e. about a severe disease or congenital defect, many parents turn to the fastest possible termination of the difficult situation through the legalised possibility of abortion (eugenic abortion, therapeutic abortion). Both the medical staff and the closest environment see no sense in continuing a pregnancy if the child is going to die shortly anyway,

arguing that abortion aims to limit the pain of the child and the parents. Parents who decide to give birth to the child despite a bad prognosis are usually dramatically lonely and suffering. For over a decade, Poland has been developing perinatal palliative care, first introduced by the Warsaw Hospice for Children (20 years ago). The concrete experiences of the Little Prince Lublin Hospice for Children, led for over 15 years by a Franciscan and psychologist, dr. Filip Leszek Buczyński, show how effective the prenatal and perinatal care provided by a hospice may be. The hospice gives parents the opportunity of various incomparable parental experiences and having memories that, although painful, are concrete and are an integral part of their family history. This hospice has been cooperating with the obstetrics ward of the Lublin hospital. Parents who receive an unfavourable prenatal diagnosis, if they wish, remain under the care of the hospice for as long as necessary, both before their child’s birth as well as after it is born and during the mourning period after the child’s death. The hospice offers multi-aspectual support of professionals and volunteers: medical, therapeutic, psychological, material, social, legal, spiritual assistance, as well as equipment, meetings with parents who have had similar experiences (so-called piloting parents). When an incurably ill child is born whose life expectancy is short, and a hospital stay would no longer improve his or her health, the hospice offers continuous help (24h, 7 days a week) so that a newborn is able to stay at home and be cared for by the family and live all of his or her short life in the “family nest”. Information on the enormous amount of good that both the staff and the patients experience at the Little Prince Hospice in Lublin may be seen at the website (www.hospicjum.lublin.pl), facebook profile or in the brochure entitled “Mały Książę”. At present, the hospice provides care for almost twenty children. The parents appreciate the hospice assistance very much, because it enables them to express their affection to the child, to have their own memories of the child, and the child can become a part of their family history. Although the child is with them for a very short time, it gives them a “lesson of life” and changes them, their goals, values and sense of life, and it deepens their view at reality. The time with the child, even if very short, often results in a spiritual renewal, like a retreat, which consolidates the family and affects their whole future life.

The Polish Association for the Persons with Mental Disability

This organisation, founded by Krystyna Mrugalska, a mother of a child with mental disability, has been operating in Poland for decades and has grown into a very large initiative – at present it has ab. 130 local clubs throughout the country. The association runs 29 Centres of Early Intervention (11,000 children), 64 Therapy-Education Centres (3,000 students), 35

Community Self-Help Homes for persons with more severe disabilities (1,000 persons), 84 Occupational Therapy Centres (3,400 participants), 4 centres of Vocational Assistance and Support for Persons with an Intellectual Disability, 6 Centres of Vocational Activity (200 persons), 30 Day-care Activity Centres (1,100 participants), 26 houses or training flats (500 persons) and 1 Therapy-Resort Centre. The association supports the movement of self-advocacy, i.e. persons with disabilities represent themselves in matters concerning them. It also organises trainings, conferences, prepares reports, and publishes the quarterly "Społeczeństwo dla Wszystkich" [Society for Everyone].

An example of the involvement of this organisation is the club in Tomaszów Lubelski, a small town about 100 km away from Lublin, which is 20 years old and undertakes various activities for the equal chances of persons with a disability and their dignified life, supports families and creates a positive image of persons with an intellectual disability by cooperating with the local environment. The club also carries out systematic workshops for parents of persons with an intellectual disability (20 hours of sessions twice a year). These are weekend sessions run by a psychologist and a priest, aimed at personal development, greater introspection, the development of ways of coping with difficulties and stress, enriching the weakest resources. Parents are offered a popular lecture, a question-answer round, a film, as well as a discussion and group work on issues of their own choice; including mutual sharing of experiences. An important aspect of the meetings is also the parents' spiritual development through the opportunity of common prayer, meditation over specially selected spiritual texts, holy sacraments, personal conversation with a psychologist and a priest. The feedback of parents points to an important function of these meetings – they allow the parents to stop in the course of daily life, rest from the everyday problems, invest in themselves, "charge the batteries" and re-discover the sense of their daily efforts, see their problems in the perspective of other people's problems, make friends, and altogether receive support of a multiple type. The long presence of a psychologist and a priest with them and only for them, as well as their presence for each other, is especially valuable for the parents.

State group home in Lublin (10 Miernicza St.)

Polish society traditionally is very much family-oriented and this is a family which is a main caregiver in cases of disability or old age. However, when disabled people get older, their parents are not usually able to look after them – being themselves old. The siblings do not always share their parents' view on devoting their life and vocational career to take care for the disabled family members. At the same time for Polish people it is still a difficult thing to decide to apply for a place in a social welfare home for their family member, as usually they are segregated total institutions of

more than 100 inhabitants, located somewhere in the outskirts of the towns.

Family-like social welfare homes seem to be a good solution then. These are small institutions for 15-20 people of similar kinds of challenges, e.g. intellectual disability or psychiatric disorders. They can be governed by local authority or NGO's. People living there are supported by the staff (psychologists, pedagogues, social workers and caregivers), but are advised to take as much responsibility as they can for their daily living. It includes cleaning, cooking, laundry and other housework. They spend their days outside, working in the community in workshops or supported job placements.

One of such institutions is a group home in Lublin. It is a state institution, although at the beginning it was governed by an association. It was founded in 1992 and is located in a semi-detached house in one of Lublin's suburban districts. It is a four-storey building, there are 11 single or double rooms there, three kitchens and the living room. The house is prepared to host 19 inhabitants, adult people with mental disability. Today 18 persons live there, their age varies from 20 to 43. Nine of them lived in other institutions before coming to the group home, as their parents either abandoned them at birth or they were deprived of parental rights. Nine of the inhabitants came to the Miernicza Home from their family homes, four of them had a pathological family (alcoholism, domestic violence, parents' lack of ability to cope with everyday problems), five were forced to leave their family homes because of the death or serious illness of their parents. Living in the group home was not a free choice for any of the inhabitants: the decision was taken by their caretakers.

The atmosphere in the group home is totally different from the one in a total institutions. Life is more similar to everyday life in a family: housework is shared and the inhabitants feel non-anonymous and secure. They take care of their rooms and the halls, possess a lot of private things (like pictures, CDs, toys, clothes etc.) which makes their life similar to this of their family members (Domagała-Zyśk 2006a, 2006b). The fact that the home is situated in a residential area helps to feel like other neighbours do. The relationships with the staff are more informal: they stress they are not only on duty, but are a kind of home inhabitants.

L'Arche "family-like" communities

L'Arche movement was initiated by Jean Vanier, a philosopher, a theologian and a former navy officer of Canadian origin. In 1964 he decided to change his life radically and started living in a small house with two intellectually disabled persons. At the beginning, he treated this act as a charity gesture but soon discovered that this relationship – of a well-educated scientist and a person with intellectual problems but warm heart – might be a source of development and happiness (Vanier 1985). Soon afterwards more people wanted to experience this radical change and

live temporarily with intellectually disabled persons together with Jean, supporting them in their daily living but at the same time receiving their kindness and respecting theirs, and their own vulnerability.

Today L'Arche have small family-like homes for intellectually disabled persons in 146 countries all over the world and it is a registered movement, cooperating with local authorities, health services and state agendas. Each home is inhabited by several disabled persons and their assistants - volunteers. All inhabitants work together in local workshops and do together all everyday chores. One of the most important rules in L'Arche communities is to work and celebrate and live together, which means that the assistants' work cannot be treated only as nine-to-five support, but real relationship of friendship and love. Nowadays in Poland there are three L'Arche homes, all of them enjoy a high esteem especially from the parents who long to have this option available for their handicapped children.

Conclusions

Disability is a universal human experience. To some extent it is dependent on the state of health and fitness, but to a large extent its consequences depend on barriers - legal, economic, architectural, educational. They all have their source in mental barriers such as stereotypes, prejudices, myths about different types of disabilities. Reasons for these mental barriers are very diverse, but their source is mainly not personal experience, but lack of knowledge about disability and lack of contact with people with disabilities.

Investment in a person always brings profit, not loss. Therefore, preventing the exclusion of people with disabilities we should pay attention both to disabled and non-disabled people. Both these groups need to acquire adequate knowledge about the constraints and possibilities imposed by disability, to intensify their positive interaction (to meet, establish and maintain communication and consolidate the social bonds), create a real picture of disabled people in society. The transformation of the ambient attitudes towards disabled people and their real social inclusion is possible if the relationships are based on the personalist approach to people with disabilities and when we will see in each of them not only a physical, mental and social dimension, but also spiritually. The bio-psycho-social model of disability should be supplemented with a spiritual dimension, if a disabled person is to be regarded as a human being. Quality of life and life satisfaction depends primarily on the sense of life, having high life goals and serving timeless values.

References:

1. Barnes C. (2003), *What a difference a decade makes: reflections on doing "emancipatory" disability research*. Disability and Society, No 18 (1), pp. 13-17.
2. Chudy W. (1988a), *Powołanie osoby niepełnosprawnej w nauczaniu papieża Jana Pawła II*. In: D. Kornas-Biela (ed.), *Osoba niepełnosprawna i jej miejsce w społeczeństwie*, pp. 123-149. RW KUL, Lublin.
3. Chudy W. (1988b), *Sens filozoficzny kondycji człowieka niepełnosprawnego*, In: D. Kornas-Biela (ed.), *Osoba niepełnosprawna i jej miejsce w społeczeństwie*. RW KUL, Lublin, pp. 105-122.
4. Domagała-Zyśk E. (2006a), *Młodość – dorosłość – starość w sytuacji niepełnosprawności*, In: J. Stala, E. Osewska (eds.), *Rodzina – bezcenny dar i zadanie*. Polskie Wydawnictwo Encyklopedyczne, Radom, pp. 703-723.
5. Domagała-Zyśk E. (2006b), *Osoba chora, niepełnosprawna, cierpiąca jako wezwanie do poszukiwania sensu. Nauczanie Jana Pawła II w kontekście „teologii niepełnosprawności” Jeana Vaniera*, In: J. Śledzianowski, T. Sakowicz (eds.), *Jan Paweł II stróżem ludzkiej rodziny*. Zakład Profilaktyki Społecznej i Resocjalizacji Akademii Świętokrzyskiej, Kielce, pp. 149-162.
6. Kirenko J. (2001), *W stronę społecznego modelu niepełnosprawności*, In: Z. Palak (ed.), *Pedagogika specjalna w reformowanym ustroju edukacyjnym*. Wydawnictwo UMCS, Lublin, pp. 61-68.
7. Kornas-Biela D. (1988), *Wczesna pomoc psychopedagogiczna rodzinie dziecka z upośledzeniem umysłowym*, In: D. Kornas-Biela (ed.), *Osoba niepełnosprawna i jej miejsce w społeczeństwie*. RW KUL, Lublin, pp. 61-77.
8. Kornas-Biela D. (1999), *Posłannictwo osób niepełnosprawnych w nauczaniu Jana Pawła II*, In: *Materiały z Kongresu Osób Niepełnosprawnych Diecezji Legnickiej*. Edytor, Legnica, pp. 23-39.
9. Kornas-Biela D. (2001a), *Osoba niepełnosprawna, chora, cierpiąca: nauczanie Jana Pawła II*, In: D. Kornas-Biela (ed.), *Rodzina: źródło życia i szkoła miłości*. Towarzystwo Naukowe KUL, Lublin, pp. 357-384.
10. Kornas-Biela D. (2001b), *Rodzice wobec diagnozy uszkodzenia słuchu u dziecka: doświadczenia rodziców, pomoc profesjonalistów*, In: D. Kornas-Biela (ed.), *Rodzina: źródło życia i szkoła miłości*. Towarzystwo Naukowe KUL, Lublin, pp. 459-477.
11. Kornas-Biela D. (2006), *Niepełnosprawność w rodzinie – czym jest, co znaczy, trudne początki*, In: J. Stala, E. Osewska (eds.), *Rodzina. Bezcenny dar i zadanie*. Polskie Wydawnictwo Encyklopedyczne, Radom, pp. 638-683.
12. Kornas-Biela D. (2012), *Hospicjum perinatalne jako forma afirmacji życia*, In: J. Stala (ed.), *Życie i śmierć. Wyzwania działalności charytatywnej*. Wydawnictwo Polihymnia, Seria „Formacja socjalna”, Tarnów, pp. 201-216.
13. Kowalik S. (1996), *Psychospołeczne podstawy rehabilitacji osób niepełnosprawnych*. BPS, Interart, Warszawa.
14. Maciarz A. (1984), *Wybrane zagadnienia rewalidacji dzieci*. WSP, Zielona Góra.

15. Rieser R. (2008), *Implementing inclusive education*. Commonwealth Secretariat, London.
16. Spaemann R. (2001), *Osoby. O różnicy między czymś a kimś*. Oficyna Naukowa, Warszawa.
17. Twardowski A. (1999), *Sytuacja rodzin dzieci niepełnosprawnych*, In: I. Obuchowska (ed.), *Dziecko niepełnosprawne w rodzinie*. Wydawnictwa Szkolne i Pedagogiczne, Warszawa, pp. 47-51.
18. Wojtyła K. (1982), *Miłość i odpowiedzialność*. T. Styczeń SDS, J.W. Gałkowski, A. Rodziński, A. Szostek (eds.). Towarzystwo Naukowe KUL, Lublin.
19. Vanier J. (1985), *Wspólnota*. Michalineum, Kraków.
20. Vanier J. (1999), *Każda osoba jest historią świętą*. Wydawnictwo „W drodze”, Poznań.
21. Vanier J. (2006), *Zranione ciało. W stronę uzdrowienia*. Wydawnictwo św. Stanisława BM Archidiecezji Krakowskiej, Kraków.
22. Vanier J. (2011), *Wspólnota miejscem radości i przebaczenia*. Wydawnictwo „W drodze”, Poznań.
23. Vanier J. (2010), *Mężczyznę i kobietę stworzył ich*. Wydawnictwo „Święty Wojciech”, Poznań.