

Support for Adults with Disabilities

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Abstract

This paper is a hermeneutic analysis of selected academic publications. This paper examines a number of issues related to undertaking social roles by adults with disabilities and the problem of their postponed transition to adulthood, restricting or delaying developmental tasks typical of adulthood, which has negative implications and may exacerbate disability. Support provided by various entities and institutions may reduce existing barriers and enhance their social integration. Both positive and negative effects of using social support by people with disabilities have been pointed out. Sources of social support have been listed along with their specifics. The analysis included the disabled person's gender, as it determines the nature of support and its reception. Finally, the need for personalised support was emphasised along with risks resulting from institutional discrimination. The role of local community was highlighted as it corresponds to the concept of community-based support and the need to promote various initiatives aimed at integration and normalisation of life for people with disabilities.

Keywords: *adulthood, person with disability, issues, social support, normalisation, integration*

Support for adults with disabilities

Studying the situation of growing up and transition to adulthood of people with disabilities, researchers have identified numerous challenges and obstacles that these people faced with regard to undertaking social roles.

The survey on models of social functioning of people with disabilities or with long-term health conditions carried out by the Legal Services Commission revealed that in comparison to the non-disabled they were less educated, less often in employment, but were more often beneficiaries of various welfare systems, and less often reported the will to have children. More often than the representatives of the non-disabled sample they reported experiencing problems such as: discrimination, unemployment, poor relations with neighbours, difficulties in becoming tenants, homelessness, poverty, problems with obtaining social security benefits, domestic violence, neglect by healthcare institutions, mistreatment by social control services, mental health issues. There was also a risk of developing a spiral of problems, which demonstrated itself in the disabled people experiencing two or several of the above-mentioned problems at the same time, while there were also links between the situations that caused the said problems. Consequently, four groups of problems were identified across a range of domains: family issues, problems connected with homelessness, health and social security problems, and those regarding economic factors (O'Grady, Pleasence, Balmer, Buck, Genn, 2004, 19: 264–266).

Problems regarding the transition to adulthood of people with disabilities are mostly characterised by the fact that social roles are adopted later in life, in a delayed manner.

Among people with disabilities we can observe (Rękosiewicz, Brzezińska, 2011/4: 103) either restricting such demonstrations of independence and adulthood by the environment, which is often driven by fear or misunderstanding resulting from insufficient knowledge, or the close environment and the general public falsely interpreting the fact of delaying or avoiding undertaking developmental tasks typical of adulthood as a manifestation of their disability, understood as an inability to accomplish these tasks. Therefore, delayed transition to adulthood of people with disabilities is not always a result of their own choices, decisions or a means of adapting to the requirements of, e.g., the labour market, but it at times results from the impact of the family environment, neighbours, school, who fail to propose actions that are appropriate for their needs as well as abilities. Moreover, these environments can restrain their natural tendencies to learn independence, to experiment with social roles, or attempts to pursue “adult-

like” forms of activity. This attitude is normally displayed toward people with intellectual disabilities, typically perceived as helpless, dependent and incapable of becoming fully grown-up persons. The obstacles, either real or those resulting from the lack of understanding and support appropriate for the needs of the disabled, in undertaking developmental tasks typical of adulthood exacerbate the sense of being different and lead to developing one’s identity around the awareness of one’s limitations and deficits, rather than around one’s strengths and already acquired competences. Thus, the disturbed transition to adulthood becomes a secondary consequence of disability which further exacerbates it. Consequently, in people with limited ability both physical (less often) and intellectual (more often) we may talk of a delayed, or even suppressed, transition to adulthood, understood as a postponement resulting not from one’s own will, but rather as a necessity caused by one’s inability to overcome barriers in the environment.

It occurs that people with disabilities completely fail to make a transition to adulthood in the period appropriate for their age, and thus remain dependent on their parents, maintaining roles characteristic of children rather than adults, which may be due to their difficult mental and social situation as well as limitations in terms of their abilities, and the limitations of the socialisation process taking place in their family home and educational institutions and care facilities.

Karin Barron (1997: 3) claims that western society attaches great importance to the existing gender patterns, and therefore expectations toward disabled girls/women differ from those toward disabled boys/men, which results in different life opportunities in these two groups.

The process of socialisation of disabled boys and girls to social roles undertaken in adult life varies depending on the time when they became disabled and the reason thereof.

According to M.L. Beleza, difficulties which disabled men and women face are not the same, as they stem from different causes and largely depend on the social roles stereotypically assigned to men and women. Beleza claims that women with limited abilities suffer from a disadvantageous cumulative effect of discrimination factors. Disabled women experience the same forms of discrimination as their non-disabled peers, but additionally encounter the same obstacles as disabled men. Women are often, to a larger extent than men, treated as individuals incapable of being self-sufficient and needing support (Beleza, 2003).

The research conducted (Nowak, 2012b: 369–374) among adult women with visual impairment and mobility impairment confirmed the existence of challenges related to fulfilling social roles, acquiring professional qualifications, gaining professional experience, employment commensurate with their qualifications and

abilities, as well as problems related to satisfying social security needs. The area that proved difficult for the disabled women was their personal and sexual life, as well as marriage. The social activity of the subjects, understood as undertaking social roles characteristic of adults, mirrored the process of their social exclusion. The experts – social workers (Nowak, 2012a) working with disabled women also identified numerous barriers in their social functioning.

It is worth noting in this context that there is a number of existing challenges. It is still not rare that people with disabilities are treated as objects: their dignity and the value of their lives is diminished, in many situations their humanity is seen as incomplete (Brigham, Kauffman, Mcgee, 2004).

People with disabilities are still not perceived in terms of ordinary, everyday social interactions, but as “others”, which means they are treated as objects rather than as subjects, they are seen as “welfare recipients” rather than free individuals, making a valuable contribution to the achievements of civilization (Sprague, Hayes, 2000: 671–695).

Disabled people are assumed to be weak (both physically and mentally, timid, insecure) and suffering from social isolation (suspiciousness, secrecy, seclusion), frequently they are believed not to have reconciled with their situation, to mourn for the lost ability, they are seen as unhappy or jealous of the non-disabled. The stereotype of a person with mobility impairment in the United States suggests that such a person is dependent on others, isolated and emotionally unstable (Shannon, Schoen, Tansey, 2009: 75:11–18).

By reinforcing stereotypes concerning people with disabilities, social attitudes, expectations and demands are created, thus affecting their behaviour and close environment. Due to their stigmatising function, stereotypes, negative attitudes, obstacles and barriers increase the risk of social exclusion of people with disabilities in numerous spheres of social life.

As T. Żółkowska (2004) points out, along with the growing impact of the humanistic paradigm of disability, the importance of support as a determinant not only of common human sensitivity to the needs of others, but also of an organised system of institutions and services corresponding to the broadly defined concepts of normalisation, independent living and integration, becomes increasingly clear.

People with intellectual disabilities may need support primarily due to their lack of autonomy. The idea behind the support they are offered is to help them realise the potential of autonomy (Petner-Arrey, Copeland, 2014, 3: 39). People with severe and profound intellectual disabilities spend most of their time isolated and disengaged. Hence, the quality of their life is largely determined by the nature

and quality of support (Beadle-Brown, Leigh, Whelton, Richardson, Beecham, Baumker, Bradshaw, 2015, 29 :409).

The sources of support are usually divided (Cunningham, A. Barbee, 2000) into: family, e.g., husband, wife, parents, siblings and more distant relatives; groups of friends from outside the family, social groups, neighbours, superiors at work and work colleagues; religious groups; members of the caring professions, e.g., therapists, doctors, and social workers.

It is highlighted that women benefit from social support more than men. Contrary to men, women are also more satisfied with the support they receive from friends and other members of their social network. They more often mention their children, family and friends as a source of support. However, this situation is reverse in marriage – men mention their wives as a source of satisfactory support more often than women mention their husbands (Kahn, 1994: 163–184).

Women have a more developed sense of personal responsibility for the problems of other members of their social network, which prompts them to help in solving these problems. They may depend on the help of relatives to a greater extent than men, whereas men are more dependent on their wives, and when a man is unmarried he may feel more isolated or less capable of taking proper care of himself (Barer, 1994: 29–40).

Women are able to find considerably more sources of support than men, they use them more willingly and more intensively, they are more spontaneous in expressing their emotions, more effective in seeking additional sources of support – this results from social patterns and stereotypes, according to which a man should not show weakness. It is also worth noting the gender-dependent direction of social support in stress situations. Social support at work is a stress buffer for men, whereas for women a more significant stress buffer is social support received from their spouse/family (Barer, 1994).

It may be concluded that social support at work has a more advantageous effect on men than on women in terms of shaping the work-family balance. What matters here is the perceived organisational support, defined as the employee's beliefs concerning the extent to which the organisation appreciates his contribution and cares about his well-being (Aryee, Srinivas, Hwee Hoon, 2005:90).

Social support in relation to marriage may be considered as sensitivity toward the partner's needs (a disabled wife), and more specifically as acts of care, validating or confirming the partner's worth, her feelings and actions and those which facilitate dealing with problems by providing them with information, help or with material, concrete resources or means. This sensitivity contributes to building trust and various expectations based thereon, including expectations to satisfy the needs

which may emerge in difficult, stressful situations, as well as those resulting from the woman's disability. Social support in marriage may at least indirectly affect mental and physical well-being of both partners, thanks to the improved quality of their relationship and consequent level of satisfaction. Men usually receive more social support in marriage than women, whereas wives provide their husbands with more support than they receive (Aryee, Srinivas, Hwee Hoon, 2005:90).

The form of support that is most appreciated in marriage both by men and women is acceptance. It is worth noting that women who were professionally active highly appreciated any help of their partner in everyday chores and problems typical of the family environment (Cutrona, 1996).

While carrying out research among groups of people with intellectual disabilities and physical disabilities T. Lippold, J. Burns (2009: 463–473) found that adults with ID had more limited social networks than those with PD, but they engaged in more activities (e.g., shopping, using public transport, active ways of spending free time, etc.) than people with physical disabilities. Moreover, the researchers discovered that people with intellectual disabilities mainly relied on social support provided by their families and carers. The intellectually disabled were shown to have few relations with non-disabled people, whereas in the case of people with physical disabilities it was found that the ratio between relations with non-disabled people and the relations with other disabled persons was more balanced. The authors (Lippold, Burns, 2009) drew several conclusions concerning social support: intellectual disabilities are accompanied by phenomena and processes leading to a more impoverished lifestyle with regard to social relations (despite their greater engagement in various activities compared to people with physical disabilities). For people with intellectual disabilities integration and engaging in a wide range of activities does not grant good social and emotional support. Despite assistance provided by numerous carers, adults with intellectual disabilities do not develop their social networks compared to those formed by people with physical disabilities. Hence, the type of disability affects the type and quality of social relations and this is, unfortunately, especially conspicuous in the case of people with intellectual disabilities.

The research conducted showed that women with disabilities (mobility and visual impairments) use various sources of social support, they mention their children, spouses, parents (if living together) and friends as primary sources of support (Nowak, 2012b).

Social support is a phenomenon accompanying people with disabilities throughout the course of their lives. The possibility to receive support helps a person with disabilities to prevent isolation, exclusion, increases their mental strength, may

prove an effective way to integrate social roles fulfilled by these people, especially their professional and marital roles. Skilled support fosters development and proper adaptation of an individual to a challenging situation.

Active support is most desirable. Beadle-Brown, Leigh, Whelton, Richardson, Beecham, Baumker, and Bradshaw (2015, 29: 420) claim that active support is an integral part of assistance provided for the intellectually disabled, regardless of the degree of their disability.

While exploring the issue of social support, it is also worth looking at the negative implications thereof. For some people social support may be a source of embarrassment and emotional discomfort. Some people may perceive such attempts as a proof of their dependency, need for commitment, and even inferiority, especially when they are unable to meet the demands of such a commitment. In these situations the persons receiving support experience embarrassment instead of gratitude, and consequently may even begin to dislike the person providing support (Campbell, Simpson, Boldry, Kashy, 2005: 510–531).

As Petner-Arrey and Copeland (2014, 3: 47) point out, ultimately the support for people with intellectual disabilities provided by institutions prevails over their need for autonomy and thus creates persistent obstacles for promoting autonomy of people receiving support.

It appears that the provision of support for people with intellectual disability and their use of various forms of support may be hindered by institutional discrimination. P. Alcock, A. Erskine, and M. May point out to institutional discrimination as a consequence of institutional social actions. They claim that policies and activity of public or private organisations, social groups and all institutionalized forms of social life lead to unequal treatment or unequal opportunities of the non-disabled and the disabled, and that social welfare institutions deprive people with disabilities of their right to autonomy. Such unjust treatment of people with disabilities is, in the authors' opinion, a consequence of statutory obligations pursued by the social welfare services which interfere with the privacy of disabled persons due to a variety of legislative acts, inappropriate and categorizing actions (Alcock, Erskine, May, 2003: 317). The financial and medical assistance offered to the disabled by a number of institutions, though necessary and often indispensable, is nevertheless a meagre compensation for their marginalisation – depriving them of independence, dignity and respect associated with active participation in community life (including employment) to an extent comparable to the opportunities enjoyed by their non-disabled counterparts (Ingram, 2006).

The disabled should be able to benefit from all schemes and systems available for the public. It is recommendable that a personalized and individually tailored offer

should be prepared and implemented for the disabled, by which their presence in the community could be enhanced, their social and professional competences improved, their ability to undertake social roles fostered and by which they could be relieved from the state of helplessness or exclusion. The most advantageous conditions for development and living can be created in the local environment, their place of residence, which corresponds to the concept of providing community-based support, and is confirmed by research. For example, Beadle-Brown, Leigh, Whelton, Richardson, Beecham, Baumker, and Bradshaw (2015, 29: 410) claim that “Following the move from larger congregate settings to smaller-scale services in the community, people with intellectual disabilities typically experience better outcomes across almost all quality of life domains.” It is indispensable to include their families, neighbours, mutual support groups, local authorities, agencies responsible for healthcare, education, welfare and employment in the provision of support, and also to influence people with disabilities and the environment in which they live through promoting initiatives encouraging their social integration and normalisation.

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