

THE SOCIAL UNIVERSE OF ADOLESCENCE IN THE CONTEXT OF PHYSICAL DISABILITY



Sociologie

Mihai-Bogdan IOVU

**THE SOCIAL UNIVERSE OF
ADOLESCENCE IN THE
CONTEXT OF PHYSICAL
DISABILITY**

Lumen

Iași 2007

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Scientific coord. Maria-Roth Szamoskőzi

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ABSTRACT

Statement of problem: The scientific problem which is the object of this paper is the social universe in the case of physical disabled and nondisabled adolescents. The aspects taken in consideration are structure and motivations that stay at the base of such a construction.

Objective: The paper aims to give a conceptual frame which could allow a better understanding of the life of disabled adolescents and also to present a methodological view which could be used in future studies on this theme.

Method: The methodology we used is a combination of quantitative and qualitative approaches, with emphasis on qualitative. Five physical disabled adolescents (from one recuperatory Day Centre from Rm. Vâlcea city) and five nondisabled adolescents were asked to complete 3 worksheets ('family flower', 'spiral of friends' and 'institutional map') in order to assess the structure of their social universe. Then they were asked to complete RSE test in order to evaluate the manner in which they represent themselves. In the end we realized two case studies (one from each initial group) in order to have a complete image over the experience as a disabled/nondisabled adolescent.

Results: first, we revealed different manners of conceptualizing the familial universe and friend-group. Implicitly this gave to the two social realities different in structure and functionality. For disabled adolescents 'family' is first represented as a nuclear family and then as a large unit. Family structure is limited and its purpose consists in mainly assuring the basic needs (protection/overprotection). This ultimately leads to reducing functional autonomy of the physical disabled adolescent. Although a quantitative analysis would justify the social integration, in the case of group friends, the quality of these relations is shallow. For non disabled adolescents the family

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structure is richer and also it extends it to the distant relatives. Nondisabled adolescent seems more autonomous even if we talk about making personal decisions. As for the group friends, these are very strictly selected, regarding the previous experience. All these elements are also translated in the institutional map (radial for disabled adolescents and web for the nondisabled). Self-esteem seems to be an important variable in construction of their social universe. There are significant differences ($t_8=6.04$; $m_{dis}=19.60$; $m_{nondis}=33.40$) between disabled and non disabled adolescents, meaning that the nondisabled report a higher psychological comfort about the self which later is translated in the relations with the exterior.

Conclusions: In spite of this research's validity and reliability limits these data would deserve a more detailed analysis. The theoretical and methodological step still managed to show interesting findings regarding the social experiences as a physical disabled/nondisabled adolescent.

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1. INTRODUCTION

1.1. Theme

This paper aims to identify the personal, institutional and group elements which compose the social geography of adolescent with physical disabilities.

The research questions regard:

- What is the manner in which the social universe of the adolescent with/without physical disabilities is structuring itself;
- Which are the factors that contribute to such a structure?

1.2. The importance and the present interest of the subject

The first question which can be raised is what the theoretical and practical relevance of this topic is. In answering this we will address two elements: the statistical data and the present social dimension of the rehabilitation programs. So, it is estimated that there are 500-650 million persons with disabilities in the world, approximately 10% of the world population, 150 million of whom are children. More than 80% live in developing countries with little or no access to services (Committee on the Rights of the Child, 2006). Considering this, the great interest in childhood research (James, A., Jenks, C., Prout, A., 1998; Mayall, B., 2001, 2003; Corsaro, W., 2005) it is justified. The Institute of Medicine, Centers for Disease Control, Healthy People 2010, and the World Health Organization have all identified disability as important area for research and targeted interventions (Lutz, B., Bowers, B., 2005). Much more, the rule 13 from the Standard Rules on Equalization of Opportunities for Persons with Disabilities states that we need collecting and disseminating

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information on the living conditions of persons with disabilities and promoting comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities¹.

In Romania's case, although children with disability have become more visible since the beginning of transition and attitudes towards them and their families were changing, many of them simply remained "written off" from society (UNICEF, 2005). Despite the stipulations of the United Nation's Convention on the Rights of the Child (CRC)², the Draft Convention on the Rights of Persons with Disabilities³ and Romanian law 272⁴, the child with disability is still in a delicate position regarding the equality of rights, the social integration programmes and normalizing their life conditions. The community is little involved in delivering social programmes to these children. Despite the constant trials, the perception of children with disabilities is still negative (Salvați Copiii, 2006).

Beside that, statistics on disabilities are difficult to compare internationally because different countries have different definitions of disability, different degrees of political will to publicize such information and data available is mostly based on the medical model (Groce, N. E., 2004).

In EU, although the official records speak about one tenth of the population having some form of disability (CRPIS, 2005), in Romania official records (www.anph.ro) show smaller numbers. At September 30, 2006 there were 479388 persons with disabilities out of which 54817 children (11.43%) and 12487 with physical and multiple disability (22.77%). Out of the total number of children with disabilities 45159 are between 10-19 years (82.38%). In Vâlcea County there are officially 13479 persons with disabilities out of which 1804 children (13.38%), this

¹ <http://www.un.org/esa/socdev/enable/dissre00.htm>

² art. 23 (1)

³ art. 7

⁴ art. 46

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situating this county among the first ten. Out of them, 69 have physical disability and 203 multiple disabilities. It is estimated that the real number of children with disability rises to 2809.

Then, it is known that persons with disabilities in general require services from many different sources, both private and public. However, not much is known about how these systems should be design to serve the self-defined needs of persons with disabilities best (Lutz, B., Bowers, B., 2005). In Rm. Vâlcea city this state is justified by the map of the social services offered, most of them being focused on medical rehabilitation dimension, as the most urgent needs of these are those. In the north area there is a Complex of Services belonging to the D.G.A.S.P.C.⁵ where both institutionalized and non-institutionalized children benefits of medical rehabilitation. So, in spite of the social inclusion philosophy that we talked about for at least 4 years (law No. 519/2002 and law No. 448/2006) the social needs of the children had been neglected. The dimension of children as a social actor, capable to participate to its own social welfare through strong social interactions was left out. The social support network that the children is constructing during the years offers him mutual help, opportunities to communicate and emotional release by sharing similar experiences, a sense of belongingness, makes possible compassion, acceptance and love and also constructs a positive self-esteem through the continuous feedback. Or, most of the times the children comes to the Day Centre only to fulfill his rehabilitation programme and then returns home, most social interactions being those with his own family. Without denying the central role that the family plays, and should play, in rehabilitation of children with disabilities we also consider necessary a more complex interaction with other persons, at least for the reason that the family can't be always by the child,

⁵ Direcția Generală de Asistență Socială și Protecția Copilului (General Department for Social Work and Child Protection)

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therefore it is necessary to put in good use the external and internal resources in order to prevent the relapse into apathy.

The social institutions which can be interested of the results of such research are those who offer different social work programmes to persons with disabilities. In Rm. Vâlcea there are two such NGO's: Asociația de Sprijin a Copiilor Handicapați Fizic – filiala Vâlcea (ASCHF-R) and "Soul to Soul" Foundation. Other public institutions are D.G.A.S.P.C. and A.N.P.H.⁶.

⁶ Autoritatea Națională pentru Persoanelor cu Handicap (National Authority for People with Disabilities)

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2. THE CONCEPTUAL MAP

2.1. Disability – physical disability

2.1.1. Definition

Formally said, disability *is a physical or mental condition that limits a person's movements, senses or activities, a disadvantage or handicap, especially one imposed or recognized by the law* (Concise Oxford English Dictionary, 2002:406). But off the record by now there has been argued the difficulty to conceptualize “disability” in a universally accepted manner (Albrecht et al. 2001 apud. Waldschmidt, A., 2007; Merrick, J., Carmeli, E., 2003; Leonardi, M., 2004; Lutz, B., Bower, B., 2005). In 2005 UN delegates gathered to draft a Convention on the rights of person with disabilities⁷. This new UN Convention that is under work will likely create such a common understanding (UNICEF, 2005). By then in the academic literature we have a **medical understanding** which regards disability as a defect or sickness which must be cured only through medical intervention and a **social understanding** (Abberley, 1987; Oliver, 1990; Morris, 1991 apud. Priestley, M., 1998; Smith, S., 2005) developed by International Disability Movement. At a theoretical level, such an approach shifts the focus of attention away from the physical, cognitive or sensory impairments and towards the study of disabling barriers, policies and practices (Barnes, 1991; Zarb, 1995 apud. Priestley, M., 1998), asserting that the disadvantage experienced by disabled children is not a consequence of impairment but rather a failure

⁷ see the actual text on

<http://www.V1.dpi.org/files/uploads/convention/advance/AdvancedUneditedConventionText-30-08-06.doc>

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of social structures and institutions to accommodate them on equal terms. The social model has also promoted the idea that disabled people should be actors in their own lives, rather than passive recipients of care or charity. Disability becomes a dynamic concept that varies in each individual depending on the context and the resources available, is a normal aspect of life, placing the experience of disability in a broad continuum of human functioning; it is not something that happens to a minority of people, but is a universal human experience (Save the Children UK, 1997; Crystal, D., Watanabe, H., Chen, R., 1999; Merrick, J., Carmeli, E., 2003; Lutz, B., Bower, B., 2005). Most people would have experienced some degree of disability at some time in their lives. At a political level, this understanding fits within the discourse of disability rights and inclusive citizenship adopted by government and international development agencies throughout the world.

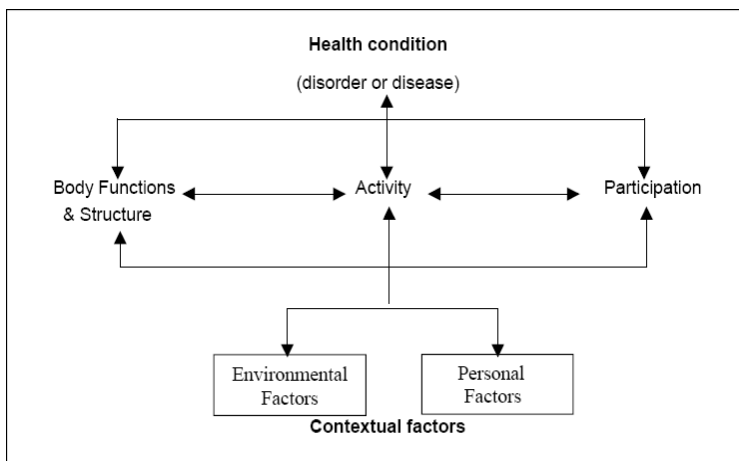
World Health Organization uses the ICF (International Classification of Functioning, Disability and Health) in an attempt to both overcome some of the aforesaid difficulties, and to harmonize the competing models outlined above. So, the ICF will also be used in this paper as a framework for conceptualizing disability. According to this, disability *is a decrement in functioning at the body, individual or societal level that arises when an individual with a health condition encounters barriers in the environment* (Leonardi, M., 2004:7). The ICF describes disability as a multi-dimensional concept, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and the factors in their environment that affect these experiences. The new conceptual framework has three components: body functions and structures, activities and participation, and environmental factors. These components are defined 'in the context of health' (AIHW, 2004). For details see appendix 2.

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Figure 2-1 The Model of Disability



Source: OMS, 2004:18

This understanding reflects the idea that to a large extent, disability is a social construct (Lutz, B., Bower, B., 2005). If you imagine "the disabled" at one end of a spectrum and people who are extremely physically and mentally capable at the other, the distinction appears to be clear. However, there is a tremendous amount of middle ground in this construct, and it's in the middle that the scheme falls apart. Between a socially "invisible" impairment - such as the need for corrective eyeglasses – and a less acceptable one - such as the need for a corrective hearing aid, there is functionally little difference. But, socially, some impairment creates great disadvantage or social stigma for the individual, while others do not. Some are considered disabilities and some are not.

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2.1.2. Classification

The new WHO classification system for health and disability casts a broad net. ICF embodies a number of new concepts compared to its 1980 predecessor pilot (UNICEF, 2005):

- it focuses on an individual's whole range of functioning from 'no impairment' to 'complete impairment';
- it does not limit itself to a medical diagnosis;
- it recognizes and measures the presence and impact of environmental factors, whether those relate specifically to the individual or to broader social aspects such as the lack of accessible buildings.

The current Romanian classification includes⁸:

- Physical disability
- Somatic disability
- Hearing disability
- Visual disability
- Deaf-ecity
- Mental disability
- Psychological disability
- Multiple disability
- HIV/AIDS
- Rare diseases

⁸ art. 85 (2) law no. 448/2006

2.1.3. Physical disability

Physical disability represents the category of impairment that especially affects one person's motrical capacity, both at neuromotor and psychomotor level, causing a series of consequences in self-esteem and in the manner he interacts with the physical and social environment. If the physical disability is not associated with other deficiencies, but instead there is strong and visible impairment, especially affecting the capacity of moving, then there can be some transformations in the process of personality structuring and in the way of relating to others. In these cases we can talk about inferiority complex symptom, depressive moods, tendency to internalize emotions, isolation, retracting in activities that can be completed by himself. The clinical canvas becomes more complex and the prognosis of evolution and psycho-physical development becomes more relative if because of the common etiology or in succession of a late recuperatory intervention and delays in educational process, the physical disability is associated with other deficiencies (in most of the cases is mental or psychological disability).

The classification of physical disability is mostly build on the etiology. From this perspective we can talk about (Neamțu, G., 2003):

- Genetic diseases
 - Langdon-Down syndrome
 - Malformations of the locomotor apparatus
 - Sprengel deformity
 - Pectus excavatum
 - Congenital sprain of the hip
- Development diseases
 - Rickets
 - Flat-foot
 - Stature hypotrophy

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