

Disabled Individuals' Family Relations — Practical, Social and Emotional Perspectives

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Abstract—The article presents the results from a qualitative study conducted in 2015 in Timiș County, Romania, consisting in interviews with 24 disabled persons regarding their experience with disability, and its reflection on their social roles as parents, family and community members, friends, interpersonal and intimate relationships. Using a qualitative research approach named "Institutional Ethnography", the current study reveal "lived" experiences of 24 people with disabilities both from cities and countryside regard problematic aspects of disability likely to influence the disabled person's status in the society. The 24 respondents provide a bottom-up perspective of how disabled persons and family members organize daily life in practice. The current paper describes the following themes: the time and financial costs, physical and emotional demands, and logistical complexities associated with disability and raising a disabled child) derived from the qualitative data using a research approach named Institutional Ethnography. The impacts will likely depend on the severity of condition as well as the emotional and financial capital of the family and the community resources that are available. The purpose of this paper is to report the preliminary findings of this research and to discuss implications for the future in terms of policy development, service planning/and delivery.

Index Terms—Disability, family, institutional ethnography.

I. INTRODUCTION

The research carried out with disabled individuals or with their caregivers showed the crucial role that family and community have on their general well-being. Using in-depth case studies, this qualitative research examined disabled individuals' family relationships. Moreover, in the current review, we present our qualitative research findings regarding disabled individuals' own families/extended families and discuss the family/community factors that account for the general well-being of the disabled individual.

The child's impairment affects the whole family. Practitioners are present only in certain moments of life of a disabled child. The biggest role in caring for a child with disability is undertaken by the family and a part of their local community willing to help the family in a difficult life situation [1].

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The family may be exhausted by the disability, physically, emotionally and financially, but with or without help, the family members are often able to renew their energies and resources and continue to function with a reasonable degree of competence. The spectrum of disability is so broad and so complicated that it is not possible to present here the range in breadth or depth of ways of identifying or dealing with all the manifestation.

This chapter endeavors only to suggest an approach to some of the common social 'problematics' of disability likely to influence individual/family/community well-being. Regarding family and community problems, we identified three specific issues, based on interviews conducted with disabled individuals or their caregivers, included in this qualitative research.

II. RESEARCH METHODOLOGY

Following the method of inquiry named *Institutional Ethnography*, our study started by investigating the everyday experiences of disabled individuals as members of families. The current report presents the findings of this specific stage, regarding the challenges faced by families in dealing with disability. In this phase, the investigators chose to use a semi-structured interactive ethnographic interview to explore the daily life experiences of adults with disabilities from the perspective of individuals and family members. The interviews with the disabled persons have guided the study according to what they inform the project research team within reference to what they consider to be the 'problematic' in their everyday family and interpersonal relations.

III. RESEARCH OBJECTIVES

The research objective guiding the research team during this phase of the investigation was to investigate how social and family relationships develop and are experienced by disabled persons. In order to meet the current research purpose the study objectives were identified broadly as follows: a) To examine the influence disability has on the private sphere of life of disabled people; b) To identify what disabled people consider as 'problematic' regarding their relationships with family members/ friends and community.

IV. PARTICIPANS

The selection of the interviewees for our study (disabled individuals) was made in two steps: (1) an initial list of cases

provided by our collaborators (two local NGOs and two local public authorities) with persons fitting the criterion “disabled individuals for which a handicap certificate was issued”; (2) the selection, from this list of cases of the interviewees fitting the criteria regarding sex (male/female), status on the labor market (active/inactive), age distribution (balanced variation for the age group 25-55), type of impairment (balanced variation for all types of impairments), area of residence. The interviews for the current report were conducted starting from December 2014 until February 2015. Between February-April 2015, a subsequent encoding and interpreting phase followed. We designed a special interview guide and participants provided individual interview. Interviews with beneficiaries were conducted by members of the research team. All interview sessions were audiotaped and afterwards

transcribed verbatim. So, our study is based on the qualitative analysis of the 24 interviews with disabled persons.

V. FINDINGS

Thematic analysis of the transcripts revealed three major themes regarding the ‘problematic’ of disabled persons’ relationships with family members/ friends and community, with a varying number of subthemes subordinated to each one. The structure of the themes and subthemes, in a quasi-chronological order, illustrated with quotes extracted from the interviews, is presented in Table I.

TABLE I: THEMES, SUBTHEMES AND ILLUSTRATIVE QUOTES FROM THE INTERVIEWS

Theme	Subtheme	Illustrative quote(s)
# 1. Inner family ‘problematics’ directly involving the disabled person	# 1.1. Arrangements for caretaking and parental burden	- He must be permanently supervised... He cannot wash himself like a healthy person, how should I not take care of him? - The child required activities and I couldn’t manage and I had to quit my job. - I even had problems when I walked down the street with him. Once, on a tram, he hit people.
	# 1.2. Empowerment vs. Overprotection	- We give him a note, he goes shopping, small quantities, small amounts. He is happy, he comes and shows me the change. - When he got home he refused to do anything you asked him to, if you gave him the broom and wanted to teach him how to sweep, he threw the broom. He refused categorically, but there [in the protected apartments] they worked with patience, now they are telling me that after he eats, they taught them to wash their own dishes, each one washes his own dish and puts it back in its place.
	# 1.3. The challenges of disability in establishing or maintaining intimate relationships	- I was lucky to find him sort of similar to me, only he doesn’t admit that he also has a minor health problem, which cannot be seen and allows him to be a normal person. - He tells me many times “Mom, had I been healthy, I would have also had a family.” - I think my daughter also separated because she has a disabled brother. My son-in-law accepted, but not his parents. - It’s difficult to find friends because... I’m afraid that they [people] don’t accept me or see me differently and try to avoid me.
# 2. Inner family ‘problematics’ indirectly involving the disabled person	# 2.1. The need for laying the ‘fault’ outside the family	- I was born in 1987, reason for which it is believed that my health problems were based by the accident in Chernobyl. - Well, I was born at 6 months and a half, [and I weighed] 700 grams. And I was in the incubator for 11 months and there they gave me the wrong vaccine.
	# 2.2. The parents’ struggle to find a ‘cure’	- We tried speech therapy, recovery, until he was 18 years old, we tried all that was possible, what we knew and where we were guided to go.
	# 2.3. The ‘making’ or ‘breaking’ of the family	- The child being ill, he also balanced our lives very much. Having a child with health problems, you don’t have time to fight or have other worries.
	# 2.4. Disability and family structure. Disrupted family dynamics	- My grandmother also wanted what was good for me, but she only had one and a half school grades and she did not realize how important school was. - I was left in the hospital when I was 2 and a half months old; other people raised me. - I lived with my parents until I turned 7 years old. And since then, I have been living at the orphanage.
	# 2.5. Inter- and intra-generational caregiving	- There’s a connection between him [disabled child] and his [non-disabled] sister and this makes us happy. When his sister was younger, she was angry because I cared more for him. - We tried to show our daughter the reality that the boy will need somebody’s help in the future, if she can offer in the future the help that he needs, and she said that her brother will be an important person in her family, he will be part of her family, and she’s not ashamed.
# 3. Outer family ‘problematics’ related to the existence of a disabled member	# 3.1. Social isolation among disabled individuals and their families	- We have fewer friends because of him because not all people accept us. - I wanted him integrated among common children, I had problems with the parents, he was not accepted.
	# 3.2. Cultural influences on the disabled individuals’ access to adequate services	- I knew what to do around the house and what was related to the house, but the rest - I knew nothing, to go somewhere. If they left me in the middle of the city, I had to ask because I didn’t know how to leave that place.

Theme # 1. Inner family ‘problematics’ directly involving the disabled person

The reality of the families having a disabled member is extremely hard and sometimes exceeds adaptive capacities of

even the more available and involved relatives. With the emergence of a disabled child, family lifestyle changes totally. The parents of disabled children have to face multiple tasks simultaneously.

Subtheme # 1.1. Arrangements for caretaking and parental burden

In the case of severe disability, the burden of care falls on the family, which is subject to continuous stress and must be able to cope without expressing emotions that could contribute to destabilization of the disabled person. The process of care, supervision and recovery being ongoing, the family must face an exhausting schedule.

Parents caring for disabled children and youth typically have extensive additional demands on their time and resources. This pressure can significantly impact their well-being. Parents of disabled children encounter stresses unlike those of families with typically developing children.

Research involving families of disabled children or special healthcare needs has identified several types of family needs. Families of children with physical disabilities most often expressed needs for information about services (59%) and their child's condition (43%) [2]. A study by Walker et al [3] showed that 91% of parents of children with chronic health conditions expressed needs for information about their child's condition, treatment and long-term implications of the child's health condition.

Parenting stress is a common characteristic of families that have a disabled child [4-5]. Other research [6], highlights; there is also a time-related burden for family members who provide round the clock direct care support or for those who spend considerable time coordinating home-based care while they remain in the workforce. According to other authors [7], parental burnout due to chronic stress appears as a confrontation with unmet family needs for a long period.

Social support interventions have been proposed as one approach to alleviate parenting stress [8]. For example, Feldman & Scherz [9] described two types of social support systems: (a) Formal social support - includes services provided by professionals such as school programs, parent education specialists, therapists, and respite-care agencies and (b) Informal social supports - encompassing relationships between family members, relatives, neighbors, friends, and community groups.

Somatic and psychological health, emotional health, quality of life and well-being have all been demonstrated to deteriorate among caregivers of those with complex disabilities [10]. The results of previous research underscores that specialists must pay also attention to the physical and mental health impacts on the parents of a child with a chronic disability.

On the other hand, problematic behavior, and the practicalities of managing these behaviors in public, prompted some families to withdraw from socializing in public places, and caused difficulties in securing childcare.

Subtheme # 1.2. Empowerment vs. Overprotection

In our research investigations we have found that parents try to estimate their children's level of functioning, that is, their potential to achieve independence in their own life. Family imposes some restrictions to the child, encourages

domestic activities and especially the self-care, and stimulates physical and social skills of the child.

On the other hand, parents may become abnormally close to the child, overprotecting, over indulging and dedicating him/her so much of their time, to the point of overlooking their own needs and their responsibilities to other people. So, as a result of parent's overprotective attitude, the child may be viewed as 'sick' and encouraged to be more dependent than it is necessary. Thus, with the best intentions and the real power of sacrifice, the parent is liable to arrest the progress of their child.

Overprotection has a negative effect on the child's independent life skills' progress, generating denials from both parents and the children. Parents, who are overprotective and overly cautious, are making the child more dependent and demanding for the family.

Subtheme # 1.3. The challenges of disability in establishing or maintaining intimate relationships

The vast majority of those interviewed highlighted the importance of identifying a mate able to accept them as they are and preferably a mate without disabilities. Many of those interviewed are married, some are in a relationship and others were in search for a relationship.

In the current cultural arrangements in Romania, the dominant paradigm for the most desirable type of existence in adulthood is the marriage. The ideal mate refers to the image that an individual constructs of the characteristics of the person he would like to marry. Privacy as a human need is generated from 'differentiation of a universal biological need, a need for physical closeness and contact with another human being' [11]. Bagarozzi [11] shows the need to develop emotional bonds with others 'seems to be a defining human trait innate and which will undoubtedly continue to manifest'.

From a psychological perspective, the ability of individuals to work, love (initiate/maintain couple relations) and develop interpersonal relations are the three expressions of individual mental health. So, marital or couple relationships contributes to individual happiness and health. Also, studies show that throughout adulthood, intimate relationship serve as a significant source of support [12] especially in times of stress.

The interviews also the struggle the informants had in finding the 'right mate'. This difficulty could also extend to the other family members of disabled person and their search for a mate.

Every disabled person goes through the process of coping with whatever challenges their impairment brings, to accept what is happening and to find ways to express also their sexuality. For some disabled individuals this could be a longer journey compared with nondisabled individuals. Disabled individuals may find often extremely difficult to start a relationship.

Theme # 2. Inner family 'problematics' indirectly involving the disabled person

Subtheme # 2.1. The need for laying the 'fault' outside the family

The recurring theme of 'medical error' is present in almost all cases. The disabled persons/parents of the disabled children usually presented a story which exempted the family from the 'fault' of producing a disabled child (fault of the doctor, the consequences of vaccines, medical errors, pelvic

births, disease in infancy contacted and treated improperly, accidents etc.). This is a coping mechanism used by parents to prevent the child's inevitable interrogations about his/her condition (why me?) and/or to avoid the feelings of guilt and to avoid accusing each other.

The birth of a child is a powerful, often exciting, intimate event in the cycle of a family. Few happenings prove to be as potent change-agent in daily living as the arrival of a new member into the family constellation. Birth of a disabled child may cause feelings of depression, disillusionment, in one or both parents. These families face an extended life crisis situation, to bring a disabled child into a world intolerant of disabled. Too often these parents deplete their own emotional and intellectual resources prematurely. Early on, to cope with this feelings, they place the 'problem' outside their reach, suppressing/denying having born a disabled child. After a while, though, they have to accept the objective situation, so putting the blame on exogene factors helps a little, because now the attention is focused towards struggling only with the feeling that an injustice was done to them.

We can note both at individual level (disabled person, caregiver) but also at their family level, representations of the urgent need to blame someone else for the causes of disability/impairment. Perhaps, this coping mechanism, to blame someone else, to find the guilty party outside the family space represents a protective factor that help them to adapt better without getting hurt their personal ego and also the family function.

Theme # 2.2. The parents' struggle to find a 'cure'

For some families who already are vulnerable, the disability/impairment of a child may produce more severe and enduring consequences. The disabled child poses special problems/challenges for the family. It is a fact of life that parents feel both responsible and guilty when a child is born with an impairment or when a chronic illness makes its appearance during the course of childhood.

It accounts for the unending search so often conducted by parents who have children with chronic conditions such as brain damage or intellectual disability; they go from one place to another seeking help, never quite able to accept the limitation of present medical knowledge and rehabilitation therapies.

Undoubtedly, a period of time their level and the quality of their social and emotional functioning are sustained by hope that somewhere a solution will be found. Feelings of loss are often delayed, appearing gradually during the period of ongoing treatment and rehabilitation.

In conclusion, we can note the parents' absorbing involvement in educational or rehabilitative therapies for their children with a disability/impairment. Moreover, families where there is a child with an intellectual disability/impairment tend to access early services for recovery in their desire to rehabilitation and social integration.

Subtheme # 2.3. The 'making' or 'breaking' of the family

The family as a whole will attempt to adjust to a child with disability/impairment without changing the existing family structure. However, family members may reach a point when ordinary social, economic and personal expectations cannot continue to be met. A role-organization crisis may crystalize

in association with a high level of tension. In such a crisis, the delicately balanced family priorities may be altered with the possibility of shifts in roles and in the division of work and responsibility. For those parents who succeed to meet this harsh experience test, being the parents of a disabled child becomes an opportunity of evolution. The child, instead of being regarded as a source of concern, becomes a source of joy. The parents change. They begin to see what is important in their lives.

Subtheme # 2.4. Disability and family structure. Disrupted family dynamics.

Family disorganization and marital conflicts diminish the chances of development and socio-economic integration of disabled individuals. Often, the disabled children are raised and educated by their grandparents who either do not have the cultural and educational level enabling them to understand the special needs of these children or do not have the adequate financial resources. Sometimes it happens that disabled children end up in orphanages or are adopted.

The type of family the baby is born/living in is very important for the child's future development: crowded conditions in the home, a large family, lack of education, family dissolution (death of parents, separation/divorce, consensual unions, single mother/father, fathers who does not recognize the child), with intra-family conflict relationships (alcoholism, violence, abuse), lack/absence of a certain source of income, are all factors that weight in and influence the path of the child towards adulthood.

In families that are disturbed because of marital disequilibrium or personal difficulties of the parents, or because of external or disadvantaging stresses that are unmanageable, difficulties result for the child. Divorce that occurs in the early years of the children's lives can be extremely hurtful to the children as well as to either or both parents, and the divorce brings special hazards to family life [13].

Subtheme # 2.5. Inter- and intra-generational caregiving.

If the level of their income allows, the parents may concentrate their economic and emotional resources on the chronically disabled child, thereby depriving other children of necessary affection.

The non-disabled sibling is often expected to take over more adult responsibilities and also the responsibility for the future care of the disabled child.

On the other hand, some parents are trying to develop positive relationships between the non-disabled child and the disabled one, inducing guilty feelings to the non-disabled child who is somehow compelled to express their commitment of taking care in the future for the disabled sibling.

Theme # 3. Outer family 'problematics' related to the existence of a disabled member

Subtheme # 3.1. Social isolation among disabled individuals and their families

Some disabled individuals and disabled child's families talk about not having friends or social network. The reaction of the community, often does nothing but complicate the situation. Friends disappear one by one because people going through a critical situation are always concerned about a single subject cannot be a company just casual. Consciously or not, society

tends to discriminate the disabled.

In addition to the considerable responsibilities of caregiving, some families report that they are excluded from family and neighborhood activities which can further isolate them from wider social networks and supports.

Members of the public community who unwittingly behave in awkward, scared or embarrassed manner in front of disabled individuals or their families reinforce this sense of isolation and can lead to feelings of guilt and shame among family members.

On the other hand, problematic behavior, and the practicalities of managing these behaviors in public, prompted some families to withdraw from socializing in public places, and caused difficulties in securing childcare.

According to the Romanian national legislation, the severely disabled person is entitled to a personal assistant.

The personal assistant can be one of the relatives of the disabled person or be a professional personal assistant (someone outside the family).

As a consequence, many mothers give up their jobs, in order to fulfill the duties regarding the caring for the disabled child, at home. For a long period of time, the only concern of the mother will be to care for the child; the contemplation of the perspective that, in spite of the special attention dedicated to him/her, the child will never be able to manage alone, even as an adult, raises feelings of anxiety and frustration among such mothers.

The role of personal assistant of the mother appears to be one in which the parent feels valuable, because of sacrificing other roles. But this is far from ensuring the satisfaction or happiness of the mother due to the fact that with time, the sphere of her interests narrows very much. Under such conditions the mother often is very absorbed in nursing tasks and in struggling to juggle the financial demands.

The lack of congruity between the professional role and between authority and responsibility appears to be a major source of parental frustration in rearing a disabled child. Findings of our research showed that raising severely disabled children reduced the time mothers had for leisure activities and highlights the mother sacrifice for the rearing of the disabled children.

Subtheme # 3.2. Cultural influences on the disabled individuals' access to adequate services

Today, although the extended family no longer functions as it once did, the central figures and the natural networks that revolve around them continue to function, with friends and neighbours replacing kin. Nearly everyone needs friends. Those who prefer solitude and the constant company of their own thoughts are exceptional.

The average person is dependent upon friends for love, approval, comfort, encouragement, entertainment. Usually the friends lie outside the family circle. Friendship requires an output in time, energy, patience, even money; but it is worth it in the satisfaction, fun, health, and happiness derived from it. So, lack of financial resources is another obstacle in a disabled person's chance of having friends and socialize outside the family life.

Secondarily, some families talk about not having a part in the community life. They do not subscribe to and do not attend community activities. For example, in many rural

communities, families have little opportunity for appropriate or adequate jobs. In Romania, some population segments, through their isolation geographically and culturally, have fewer opportunities than other groups either for employment or for exposing their children to other ways of living more consistent with the prevailing culture.

VI. CONCLUSION

The requirements the disabled child's family have to deal with in providing care and protection for their child are extremely hard and sometimes exceed the adaptive capacities of even the more available and involved parents. With the emergence of a disabled child, family lifestyle changes totally. The parents of disabled children have to face multiple tasks simultaneously.

Previous quantitative studies provided evidence that families with a disabled member are more likely to be living in poverty. The current analysis reveals some mechanisms that contribute to this situation - the low income level is generated, in some cases, by the mother's incapacity to work, due to the fact that she has to care for the disabled child, and most often she quits her job to become the personal assistant of her disabled child.

On the same note, The World Report on Disability [14] notices that, at worldwide level, very often, disabled persons experience environmental obstacles that make physical access to employment difficult. That puts some of them in impossibility to afford the daily travel costs to and from work. There may also be physical barriers to job interviews, to the actual work setting, and to attending social events with fellow employees. Due to the geographically, culturally and social isolation, disabled individuals are forced to deal with discrimination, poverty and social isolation.

Often, people living in rural areas (both disabled and nondisabled) have no public means of transportation (train, bus) to enable them to get employed in urban area. The problem of distance must be seen in terms of lack/absence of public means of transportation, which restricts not only the disabled individuals chance to get a job but also education access, dispensary and other community services. Also, there are no hospitals, for specialty physicians they have to go in town and jobs are almost inexistent. So, disabled individuals who live in the rural areas are disadvantaged in more than one way. Elements having a significant impact upon family life and the effectiveness with which family members are able to fulfil the functions expected of them includes environmental factors such as employment opportunities, educational facilities and opportunities, housing, medical care arrangements, and other institutional aspects of community life. Each of these in and of itself is important. They may spell opportunity for a family to improve its general level of living, its economic status, its mental and physical health. Despite the rapid expansion both of medical knowledge and of facilities to meet health problems, in Romania there are wide gaps in medical services at the level of many rural communities, gaps that produce serious difficulties for many disabled individuals. These gaps range from the complete absence of any medical resources to the limited availability or

accessibility of adequate health services. Thus, the lack of educational community services resources to meet the needs of the disabled children exacerbates the parental stress and the child's possibilities of rehabilitation and integration. Additionally many parents need counseling in order to understand the nature of the disability/impairment or the developmental effect and the ways in which the child's capacities can be enhanced. Parents need group discussions and family life education programs to help them to understand the faces of their problem and to learn how to cope with in day to day life.

Often, the marital disequilibrium and the functional family problems leave their mark also on the disabled child's education, culminating with school dropout or child abandonment.

The need to assist families in developing necessary skills to help their disabled children is a vital task for the professionals who provide services.

Parenting stress is a common characteristic of families that have a disabled child. The empirical data collected through our study confirm the common-sense supposition that, in order to reduce the stress and anxiety among the parents with a disabled child, a network of family support services is required. Health professionals need to adopt family-centered approaches that embrace the support needs of mothers.

The special role of mothers raising disabled children reflects their need for strong social networks, institutionalized or not, offering regular support.

This study offers also some inside knowledge on the impact of childhood disability on parent's use of time. So, we note the disabled child's family must face a stressful and exhausting schedule that puts all its members at risk for social isolation and emotional problems. The requirements of the disabled child's parent role often exceed the parents' individual resources and coping mechanisms.

When parents realize they can develop expertise, they become the natural intervention activators, and the primary change agents for their child, thus becoming confident and more nurturing caregivers.

This research showed a major anxiety towards the projections about the future, among parents of disabled children. In this context, the parents are well aware of the difficulties expected ahead for their disabled children.

In our qualitative research investigations we have found that parents often try estimating their child's level of functioning, and are usually realistic regarding the child's abilities; however, sometimes they tend to develop an overprotective attitude toward the child.

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