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Theoretical and practical difficulties in researching disabled parenting in Romania

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Abstract

This article explores the difficulties in navigating the multidisciplinary literature on disabled parents in the Romanian context with the purpose of setting a framework for investigating this topic in Romania. The article highlights the paucity of existing data on parents with disabilities and their families in Romania and suggest steps forward for researching and theorizing parental disability from a sociological perspective in Romania.

Keywords

Disability, disabled parents, difficulties, Romania

Disability is an extremely common experience, with the World Health Organization (2011) estimating approximately 15% of the global population, or over one billion people, live with some sort of impairment, while approximately 2% have a significant impairment. Understanding the various issues surrounding disability, ranging from the meaning of disability to the societal treatment of people with disabilities to individuals' coping strategies related to particular impairments, is important for creating a more integrative society. However, studying issues relating to individuals with disabilities is a challenging task for researchers, particularly in Eastern Europe when there is extremely limited data and previous research upon which to write a literature review and build an appropriate theoretical framework.

One particular issue that is gaining an increasing interest by disability researchers and advocates globally is the issue of disabled parents. Researchers in Australia, North

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America and northern Europe are studying challenges surrounding parenting, and are beginning to develop an awareness of how parents with disabilities are treated by society, particularly the child welfare system. Despite this growing interest in other parts of the world, there has been virtually no research on disabled parents in Eastern Europe, and Romania in particular. The purpose of this article is to discuss the difficulties in navigating the multidisciplinary literature on disabled parents to set a framework for investigating this topic in Romania, highlight the paucity of existing data on the topic in Romania, and to suggest steps forward for researching and theorizing parental disability from a sociological perspective in Romania.

Parental disability research globally

There is a small, but growing interest in researching issues related to parental disability. Most of the recent scholarly work comes from the disciplines of psychology, social work, and law, with research topics closely relating to their researchers' own disciplinary concerns. Psychological researchers tend to study capacity for parenting by disabled parents (Azar, Stevenson & Johnson, 2012) and/or test interventions for improving parenting (Wade, Llewellyn & Matthews, 2008), social work researchers tend to study the social support and service needs and the broader environmental context of parenting (Lightfoot, LaLiberte & Cho, 2018), and legal scholars tend to focus on the legal or policy context for disabled parents (Kundra & Alexander, 2009). Researchers from all three of these disciplines focus on discrimination faced by disabled parents, particularly in the child welfare system or the courts (McConnell, Feldman, Aunos & Prasad, 2011; Lightfoot, Hill & LaLiberte, 2010; Pannell, 2010). There have been some important findings from these lines of research, notably that disabled parents in North America, Northern Europe and Australia are much more likely to experience child welfare or court interventions, and have very little formal services or informal supports to assist them with their parenting.

What is missing from much of the recent empirical research on disabled parenting is a strong theoretical focus, likely because of the researchers' applied social science lens. However, despite a lack of emphasis on social theory, much of the applied social science research does either explicitly or implicitly reference the social model of disability, which is an approach to viewing disability as a social construct that was originally developed by Michael Oliver (1983) in the United Kingdom over thirty years ago. While the social model was not developed by sociologists and in early years sociologists were criticized for ignoring it (Barnes & Oliver, 1993), the social model grew to become one of the dominant forces for conceptualizing disability from a sociological perspective worldwide (Thomas, 2004), and is the definition of disability that underscores the United Convention on the Rights of Persons with Disabilities adopted by the United Nations in 2006. The original social model of Oliver (1983) viewed societal barriers, such as discriminatory attitudes or architectural barriers, as the main disabling feature of impairments, thus shifting the attention of disability from an individual problem to a societal problem, though of late theorists are now working at integrating the roles of both impairment and societal barriers in creating disability (Anastasiou & Kaufman, 2013). The social model is often presented in contrast to the medical model, which focuses on impairments from a biomedical perspective, viewing impairments as individual problems that need to be prevented or treated, taking emphasis off of societal responsibility for removing any sort of barrier. The social model emphasis of disabled parenting research does push the researchers to examine issues of social exclusion and societal barriers, but the research tends to be more pragmatic and action oriented (Which interventions work best? How are barriers problematic?), than theoretical.

There is also a small body of sociological investigation into disabled parenting, which tends to be separate from that of applied social scientists. Those more interested in social theory come primarily from a feminist lens focusing on squarely on mothers with disabilities. This strand of research also has some roots in the social model of disability, but is centered more directly on feminist notions of understanding motherhood, such as the role of the ideal mother. This differs from the applied social science inquiries into social roles, which primarily views these theoretical constructs in relation to social supports (Lightfoot & LaLiberte, 2011). The sociological research tends to focus on mothers with disabilities experiencing stigma related to their lack of fitting with societal norms of motherhood (Malacrida, 2009), or deviance in their move outside of what society deems as their approved social role (2015). This smaller body of work is much more theoretical than the other strand of research, though is likely less transferable across cultures.

The applied and theoretical research into this topic are actually somewhat separate, and the researchers tend to cite the literature within their own strand, even while covering the same topics. The one area in which theoretical and applied researchers overlap the most is discussion of the barriers that parents with disabilities face, whether it be stigma, social isolation, discrimination or lack of social supports. While this overall body of research does appear promising for laying the groundwork for sociological research into parental disability, there is one serious challenge. For both of these lines of research, there has been virtually no explorations into parenting or mothering outside of Western European or North American contexts, which leaves a big gap for researchers in Eastern Europe.

Disability literature in Romania

Despite the interest globally in disabled parents, a systematic review of the literature finds almost no literature on disabled parents in Eastern Europe broadly, or at all in Romania. While the existing literature from other countries certainly is informative, the theoretical explorations of disabled parenting in particular are extremely disconnected from the history or context of Romania. This is particularly problematic as the care of people with disabilities in Romania was heavily influenced from the Soviet model, "defectology", originating in the 1920s, which shaped how people with disabilities were treated by society (Vrasmaş & Daunt, 1997). Defectology was a prescriptive model regarding working with people with disabilities, particularly children, which urged professional “scientific” care of individuals with disabilities from a multi-disciplinary perspective, emphasizing the importance of experts in the care of children with disabilities over inclusion in society. While this is similar in some ways to the medical model, defectology also involved an emphasis on the deviance of disabled people from the collective norms, which differs from the conception of the medical model, and it led to the life-long institutionalization as the appropriate intervention for people with disabilities (Florian & Becirevic, 2014). Those that were not institutionalized, were kept in isolation from society in their homes. This emphasis on disability as different from the collective norm differs considerably from the medical model’s emphasis on individual pathology, though both had similar negative views of disability and encouraged reliance on experts. The legacies of defectology are thought to persist in Romania, though this has only been studied in regards to education of children. Any theorizing or research about parental disability has to take the historical context of defectology into account, and be careful about borrowing theories that don’t fit with the realities of disability within Romania.

In fact, there has been almost no research inquiry into any aspects of the lives of adults with disabilities in Romania by researchers, and only scant, and somewhat questionable data is available. Certainly, there was little research before 1989, when disability was considered nearly a taboo subject for a country that was supposed to be in full development (Buică, 2004). While there have a few explorations of disabilities in Romania, the emphasis has been primarily on children with disabilities, particularly in regards to inclusive education (Buică, 2004; Popovici & Buică-Belciu, 2013; Walker, 2011). This is indeed an important emphasis, as inclusive education has been used as a first step to transforming countries in regards to disabilities. However, it has left us with a dearth of information regarding adults with disabilities in Romania, and makes the issue of developing an appropriate theoretical framework for researching any issues for adults with disabilities, particularly parents with disabilities, problematic.

In North America, the United Kingdom and Australia, the earliest research into issues surrounding disabled parenting which was used to form their theoretical understanding of parental disability came from studies of administrative databases or court records. Ideally, this would be an appropriate first step in Romania as well.

Administrative data about disabled parents in Romania

In fact, most of our knowledge base about adults with disabilities currently come from administrative data collected by the state. According to the National Authority for Disabled Persons in Romania (further referred to as N.A.D.P), by the 31st of June 2018, there were 805,653 disabled individuals, out of a population of over 19 million adults in Romania National Institute of Statistics (further referred to as N.I.S., 2017). This figure highlights one of the reasons why conducting disability research is difficult in Romania, as the official statistics rely on people with disabilities registering as having a disability. The government is reporting a disability rate of under 5% at approximately 4.7%, substantially lower than the WHO estimates for global disability prevalence. Thus, there is a likelihood that many people with disabilities are not registering. Potential reasons include lack of awareness of how to apply for an official recognition of their disability to receive financial assistance, lack of awareness that these benefits are even available, or lack of ability to get to an office to apply for assistance due to poverty or lack of transportation can all come into play. Likewise, lack of awareness by disabled adults themselves or their family members that they have a disability, or stigma about one's disability, can also be factors. While the number of disabled adults has increased nearly 50% since 2006 (N.A.D.P. Contributors, 2018), this is likely not related to an increase in disability prevalence, but rather due to the increase of people registering. In addition, while the numbers of people receiving disability benefits is extremely low given likely disability rates, the general public might be confused about disability reporting as the mass media regularly presents cases of individuals who have systematically defrauded the disability fund, receiving undeserved money. For example, in 2010, a Mediafax journalistic investigation, claims that approximately 35,000 files were investigated under the suspicion of fraud (Bărbulescu, 2010), and a news report from Wallstreet.ro from 2012 highlighted how 1,000 people pretended to be disabled, stealing 8.2 million Euro. The difficulties in obtaining even approximate disability rates is notoriously difficult in disability research, with countries ranging in disability rates from nearly 20% to almost 2% (Mont, 2007). These difficulties can come from relying on official disability registers, like in Romania, to using imprecise definitions of disability.

Even if we assumed that the administrative data on disability in Romania was accurate, those interested in using this data for beginning an inquiry into parental disability would be out of luck, as there is no data on parental disability in these datasets. The government collects no information about whether a person with a disability has children, how many children do they have, any details about their children's disabilities or services or supports that they receive. This is not uncommon internationally, but the lack of appropriate administrative data presents logistical problems in ascertaining the scope of nature of disabled parenting in Romania. There have been calls in some western countries, notably the United States, to collect more accurate information on parental disability in order to both conduct appropriate research and to enact government policies (DeZelar & Lightfoot, 2018), but currently most countries do not collect this data.

Parental disability in legal records

In Romania, disability is defined in Law no. 448 of 2006, article 86, which claims that there are the four degrees of intensity of handicap: light, medium, accentuated, and severe, comprising the following types: physical, visual, auditory, hearing-and-speech impairment, somatic, mental, psychological/ psychiatric, HIV-based, associated handicap, and rare diseases. The same law claims that every disabled individual, regardless of their age, marital status or type of impairment, should have unfettered access to their physical, professional, educational environment, they have the right to have a personal assistant (who could also be part of the family and take over some of the disabled individuals' responsibilities), free public transportation, a legal representative or special access facilities. While this law seems mostly aspirational, there is nothing particular written in here about a disabled person's rights or restrictions in becoming a parent. It is more typical for parents with disabilities to run into issues with the child welfare policies. In Romania, Law no. 287/2009, article 508, states that, "a Family Court, only by the request from a Child Protective Services (further referred to as C.P.S.), can declare the termination of parental rights if the parents put the child's life in jeopardy, their health or development through mistreatment, alcohol or drugs consumption, abusive conduct, through severe negligence or misconduct against the best interest of children". Even more important, the Court will judge the case only based a report filed by the Child Protective Services, and a prosecutor's presence is required. Based on the public data available, the vast majority of the cases on termination of parental rights (N= 871, source: PortalJust) are dismissed. More importantly, for purposes of researching parents with disabilities, there is no access to the court records whether a parent had a disability, nor whether their possible disability might have played a role. As there is no mention of a parents' possible disability, we are unable to do the court studies that have been common in other countries to determine how parents with disabilities are treated. Court records would not to be opened for this to be an appropriate line of research in Romania.

Need for data collection to theorize disabled parenting in Romania

The lack of previous research on disabled parents in Romania, the lack of parental disability collected in administrative records or easy access to this information in court records, and the lack in the current international social theories about disabled parents that fit with the Romanian context, leaves the researcher interested in disabled parenting in Romania with little basis upon which to develop an appropriate theoretical framework. Thus, there is a strong need for the collection of original data in the Romanian context on disabled parenting from which appropriate theoretical models can be developed. For this particular issue, which is a highly sensitive topic, individual, face-to-face interviews appear to be the most effective tool. The benefits of individual interviews are vast, including the ability of the researcher to gain trust, to see nuances and patterns of speech, they can clarify certain aspects of interest, and get a better overall understanding of the individual including their other issues that might be effecting their parenting, such as gender, class or ethnicity (Lightfoot & Williams, 2009; Fernqvist, 2015). Even without these benefits of individual interviews, they would be necessary on this topic as there are no other sources of data available.

While the theories used for understanding disabled parenting in other contexts might not fit perfectly in Romania, the topics that other researchers have been studied can certainly point researchers in some directions for research in Romania. Three areas that sociological researchers might want to explore that have been particularly salient in other contests are as follows. First, as studies have found that disabled parents often have intersections with child protection, this might be an avenue of exploration in

Romania as a beginning step. Even though CPS might not be directed to legally interfere with a disabled parent in Romania, we have little knowledge about the intersections, if any, between disabled parents and CPS in Romania. It has been the norm in western countries, and would be important to understand whether this occurs or not in Romania, and if does occur, what are the reasons for this occurrence (deviance? safety?). Since Romanian court records don't include information on this, examining this through interviews of parents with disabilities and/or child protection workers is appropriate. Second, many studies in western countries have documented the social isolation and discrimination that disabled parents face. Common areas of exploration have been to focus on stigma of disabled people, the size and nature of social networks of people with disabilities and the role of the social networks in providing social supports for parents with disabilities (Mayes, Llewellyn, & McConnell, 2008). Researchers might also want to explore the attitudes about parenting with disability by others, such as family members, teachers, social workers, physicians, or the general public. In any research regarding parenting issues for people with disabilities in Romania, it would be important to also explore the historical context of defectology in shaping how disabled parenting is viewed.

Conclusion

While the lack of exploration into disability in general, and disabled parents in particular, in Romania, poses many challenges for researchers interested in studying this topic, it also presents a great opportunity for researchers. Social researchers in Romania are at this point free to break away from disciplinary boundaries in studying disabled parents, and should be encouraged to read and draw broadly from a variety of disciplines to help inform the hopefully nascent development of a theory of disabled parenting in Romania. This theorizing can draw on established theories of disability, such as the social model of disability, build on the research findings from the disciplines of psychology, social work or law, and integrate these with the historical context of Romania. Likewise, as every avenue for research is currently open for investigation regarding disabled parents in Romania, researchers have the opportunity to conduct research on a wide variety of topics, contributing to the development of future framework for understanding this topic in Romania.

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