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PhD Thesis Summary:

Mobility Impairments and Disability in the Romanian Social and Built Environment

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Key words: mobility disability; social attitudes; inclusion; accesibility; Romania.

CHAPTER 1.

Introduction

1.1. The evolution of social understandings of disability

The psychosocial understandings of disability have evolved in time, as people with disabilities found their voices in establishing collective identities, asserting their needs and defending their rights, inspiring new research, and becoming involved in the creation of social policies.

The medical approach defines disability as the result of illness and impairment. According to this approach, sickness is a deviation from the "normal" health state a person should experience and function within, while the goal of medicine is to control sickness and restore health. Although this goal was originally described in relation to acute illness, in time it has extended to the understanding and management of chronic conditions, with a profound disabling impact (Barnes, 2012). This approach has shaped representations of disabled people as "non-people with non-abilities" (Brisenden, 1986, p. 4), rather than people with different abilities which they can use to build and live a fulfilling life. It has encouraged social views of people with disabilities as being ill, weak, pitiful, or objects of charity - dependent on others, on social resources, and on medical care as central aspects of their lives (Barnes, 2012). The medicalized evaluation and management of disability have also shaped social expectations regarding the social presence of people with disabilities and the spaces they would occupy. Consequently, people with disabilities have come to be excluded within spaces designed by and for a non-disabled majority (Kitchin, 1998; Imrie, 2000).

The medical approach of disability has been widely criticized because it seeks to understand disability and to determine the course of disabled people's lives through the narrow picture offered by a clinical diagnosis and medical expertise (Brisenden, 1986; Roush & Sharby, 2011; Barnes, 2012). Besides ignoring psychological, social and environmental factors that shape the experience of disability, the medical model has also received significant negative attention because it overlooks the autonomy of the individual in making choices for their own wellbeing (Brisenden, 1986; Barnes, 2012).

The Disability Rights movement started in the United States of America in the course of the 1960s and spread its influence internationally (Scotch, 1989). It was the first to draw attention to the fact that the limitations disabled people experience are not brought on by impairment, but primarily by inequality and barriers within the social and structural environment. Independent living was promoted alongside the Disability Rights movement, as "*the ability of disabled people to participate actively in society: to work, have a home, raise a family if they wish, in sum to decide their own futures according to the cultural context within which they live*" (Heumann, & Wilkie, 1987 as quoted in Scotch, 1989, p. 393).

Through disability rights activism and growing research in the disability field, the social model of disability (Oliver, 1981) has come forward as a reaction to the perceived reductionism of the medical model. The social model distinguishes between physical impairments which are individual, and disability, which can only occur within certain social and structural contexts. The social model states that the limitations experienced by people with impairments as a result of social and structural barriers originate from negative social constructions around disability (Verbrugge & Jette, 1994; Kitchin, 1998). The social model also stresses that imperfect health is a part of human experience and diversity, and that any person could experience some degree of disability resulting from a mismatch between external environments and one's abilities (Daruwalla & Darcy, 2005). Therefore, defining disability as a violation of perfect health, and establishing perfect health as the "norm" is showed to be both improper and impractical. Instead, within the social model and through disability rights activism, disability is presented as an issue of human rights, and an experience that is spatially and socially constructed (Kitchin, 1998; Barnes, 2012).

1.2. Barriers and disparities experienced by people with disabilities

The acknowledgement of environmental factors in creating disability has led to a wider understanding of the barriers that disabled people encounter and that must be addressed in order to facilitate their inclusion. It has been shown that people with disabilities worldwide experience negative social attitudes stemming from medicalized views of disability that isolate them and lead to their discrimination in a wide variety of life domains (Imrie, 2000; Reeve, 2004). Furthermore, negative social representations of disability lead to the spatial exclusion of disabled people, because a society's beliefs and cultural norms regarding disability are reflected within its spatial planning, design, and organization (Imrie, 2000; Dune, 2012; Hartblay, 2015). Consequently, people with disabilities experience important health, physical activity, recreational, employment, relational, and general participation barriers as a result of negative attitudes and structural barriers (Basson, 1998; Unger, 2002; Williams, Vogelsong, Green, & Cordell, 2004; Schur, Kruse, & Blanck, 2005; Horner-Johnson, Dobbertin, Lee, & Andresen, 2014). Moreover, these barriers have an important psychoemotional impact, implicitly conveying to people with disabilities that they are different, inferior, out of place, unable to do things in the same way as others, and perceived as dependent on the help of others (Reeve, 2002; 2004; 2006). Overall, being limited by negative social attitudes and architectural barriers communicates to people with disability that the value placed within them by society is low (Edwards & Imrie, 2003). The internalization of social oppression and negative attitudes poses important concerns for the wellbeing of people with disabilities, as it confines their existence and self-perceptions to the way they are perceived and treated by non-disabled people and society (Brisenden, 1986; Reeve, 2006).

1.3. The Romanian context

Romania is still traversing a transition period of adapting its infrastructure to the needs of people with disability post-socialism. The socialist regime promoted a strict medical-productivist understanding and management of disability. People with disabilities were viewed as incompatible with the healthy, thriving, hard-working ideals of the communist “new man / woman”. They were deemed “defective” and “irrecoverable”, unable to be of service to the socialist society, and were excluded from society. Furthermore, disability was viewed as a social pathology, and an indicator of a society’s failure and imperfections, therefore it had to be removed from public view (Ciot & Van Hove, 2010; Mladenov, 2017b). Most disabled people were institutionalized, and some were cared for at home with their families. In both instances, people with disabilities were forced into dependent positions where they passively received some form of care and/or social assistance. The built environment was not designed with diverse abilities in mind, as it was not expected or desired that people with disabilities would participate in community life.

The communist regime collapsed in 1989, and by 2007, Romania had become a member of the European Union. Both during and after the accession to the European Union, the Romanian legislation and regulations regarding the inclusion of people with disabilities were progressively updated to meet European requirements. Law no. 488 from 2006 republished in 2008 regarding the protection and promotion of the rights of people with handicap is currently in effect, and it has been constantly updated since its first publication. The normative regarding the adjustment of civil buildings and public spaces to the individual needs of people with handicap (NP051-2012) offers clear and detailed guidelines for the adjustment of pedestrian paths, sidewalk access ramps, public transport stations, parking areas, urban equipment and furniture, vertical and horizontal circulation and related equipment standards within all types of civil and public buildings. While the term “handicap” is still widely used both in official and colloquial language, the term “disability” was officially introduced as “*impairments and deficiencies, limitations of activity and restrictions in participation, as defined by the International Classification of Functioning, disability and health, approved and adopted by the World Health Organization, and that reveal the negative aspect of the human-environment interaction*” when the Law no. 292/2011 regarding social assistance came into effect.

Although the legislative changes and the mass media contributed to the dispersion of more positive representations of disability, studies show that mass media depictions and social perceptions of disability as a tragic or dehumanizing condition and as a social pathology continue to survive (Ciot & Van Hove, 2010; Stamatin, 2010). Much of the evaluation of disability in Romania is also still heavily anchored in medical and productivist aspects, focusing on a “degree of handicap” and a “handicap certificate” that also determine the individual’s ability to work. In terms of employment, people with disabilities in Romania experience significant environmental, educational, financial and informational barriers, most of them being unemployed and many being rejected by employers (Ionescu, 2012; Tudorache et al., 2013; National Employment Agency, 2017). Furthermore, recent evidence suggests that the implementation of accessibility regulations is often lacunary or superficial, posing numerous barriers to the access of disabled people to public spaces (Ionescu, 2012; Alexandru et al., 2013). However, the social activism component of disabled communities and organizations is still underdeveloped, and the voices of disabled people are not yet a powerful presence in influencing a better social understanding of disability, and policy development and implementation. At the same time, to the author’s knowledge, there are no studies exploring the experience of living with a disability in Romania. There is still little information regarding the social and physical barriers disabled people encounter, and the perceived role of these barriers in creating disability and excluding them from participating within society.

1.4. Main objectives and research questions

The main objective of the present thesis is to expand the understanding of disability and social inclusion in the Romanian context. While the experience of disability may involve common aspects across different impairments, one's embodiment and its interaction with the built and social environment shape unique paths in living with disability (Garland-Thomson, 2011). Therefore, the present thesis focuses on the perceptions and experiences of people with mobility impairments, and on social attitudes towards mobility impairment. Specifically, the present thesis aims:

1. To investigate perceptions and experiences shared by people with disabilities in online communities regarding the Romanian social and structural context. (Study 1)
2. To explore the experience of mobility disability, inclusion and exclusion, as it is lived and expressed by individuals with mobility impairments in Romania. (Study 2)
3. To study social attitudes towards mobility disability and social perceptions regarding how the built environment welcomes disabled people. (Study 3)
4. To investigate the relationships between personal factors, perceived environmental barriers, experienced disability, and psychosocial adjustment to disability in the Romanian context. (Studies 4.1. and 4.2.)

CHAPTER 2

Study 1: Restricted mobility and unheard voices: perceptions of accessibility and inclusion*

2.1. Introduction

Persons with disabilities use online communication in order to participate in peer support, access information, and argue for their rights (Fullmer & Walls, 1994; Furr, Carreiro, & McArthur, 2016). Romania represents a fascinating case study since legislation supporting the rights of people with disability is quite new, while negative stereotypes and discrimination regarding persons with disability have long been embedded in society, and strongly enforced during the communist regime. Exploring how Romanians with disabilities represent themselves and their social inclusion in their online communication may help inform both society and relevant authorities regarding the barriers disabled people face, and the areas to be focused on in future inclusion efforts.

This study addresses the first objective of the thesis, aiming *to investigate perceptions and experiences shared by people with disabilities in online communities regarding the Romanian social and structural context.*

2.2. Methods

Data for the present study were collected from four personal blogs owned and authored by people with physical impairments, and three discussion forums that focused on the topic of physical disability and issues that disabled people encounter in daily life. After eliminating non-original, news, and commercial posts, 364 comments from 2007 to 2016 were included in the final data analysis. The selected comments are either written by disabled blog owners in first person on their personal blogs, or are suggested – through context and/or the use of first person – to be written by disabled forum members. We used comments as an analysis unit, because while forum posts tend to be shorter and focused on a single topic, a single blog post may contain multiple comments, or statements regarding different topics relevant to the present research.

We performed an inductive thematic analysis as described by Braun and Clarke (2006) on the content retrieved from discussion forums and blogs. Thematic analysis was chosen because it can be used “to identify patterns within and across data in relation to participants’ lived experience, views and perspectives” (Clarke & Braun, 2017).

2.3. Results

Four comprehensive themes emerged from the analysis. The first theme refers to *the disabling built environment*, and brings forth feelings of confinement due to the lack of or inadequacy of accessibility features such as ramps and elevators. Furthermore, disabled bloggers and forum users felt that the needs of disabled people are often being ignored, while the main interest remains to give a superficial impression that accessibility regulations are being followed. Within *the isolating sociocultural environment*, disabled people felt discriminated and rejected based on their impairments, while remaining invisible in terms of their capacities to work and be active members of society. Their attempts to voice their needs and challenge the infringement of their rights was perceived as a lack of gratitude towards the “charity” they receive. The third theme, *blaming others and the past*, suggests feelings of segregation between able bodied and disabled people, with the former being held responsible for promoting exclusion. The discrimination of disabled people and the lack of interest towards accommodating their needs within the built environment are also attributed by some bloggers and forum users to a “Romanian mentality” suggested to originate in the communist era. However, it is also highlighted that blaming others or the past for the unfavorable treatment of disabled people, no matter if justified or not, is counterproductive when it comes to making real changes. Instead, online discourses bring forth the utility of elements promoted internationally in the Disability Rights movement – rejecting the negative, medicalized social constructions surrounding disability, adopting alternative disability discourses to challenge old ones, and defending their rights in a vocal and practical manner.

2.4. Conclusions

While not being unique to Romania, the perceptions and experiences described by disabled people in online communities suggest that medical representations of disability have survived the communist regime, and continue to be enforced by pressures of productivism reframed by capitalism as a condition for autonomy and self-sufficiency, and by the stigmatization of welfare (Mladenov, 2017b). Social perceptions of disabled people as ill, inferior, or social burdens create reluctance concerning their social inclusion. Disabled people are seen as unproductive members of society that live off the help of others or the state, and their resistance to this perception is reframed as lack of gratitude on their behalf. The perceptions of forum users and bloggers suggest that disabled people are approached through a "humans as resources" perspective (Mladenov, 2017a). When society fails to recognize a wider diversity of human resources outside what is socially constructed as "normative" as useful, the "humans as resources" perspective results in the invalidation of disabled people as productive members of society, and the discouragement of inclusion efforts through the reinforcement of negative stereotypes. However, a shift in their own attitudes towards disability, a newfound focus on independent living, and becoming more vocal as a group are represented as means for disabled people to become more visible and to challenge negative social constructions regarding disability.

CHAPTER 3

Study 2: Is “different” still unacceptable? Exploring the experience of mobility disability within the Romanian social and built environment*

3.1. Introduction

Social representations of disability that are anchored within the ideology of the former socialist regime seem to pose some of the greatest barriers in the way of the inclusion of people with disabilities in Romania. Similar issues have been observed in other formerly socialist countries (Mladenov 2011, 2015, 2017a), where the medical–productivist approach still dominates social understandings of disability, impeding alternative discourses such as those established by the social models of disability (Oliver, 1999) and the movement for independent living from permeating society. Consequently, neoliberal institutional and practice transformations are deformed and superficial, thus accentuating instead of minimizing the disparities experienced by people with disabilities (Mladenov, 2011, 2015, 2017a). However, most information about the disparities experienced by people with disabilities in Romania come from external observations and surveys, while the perceptions of people with disabilities and the implications of such disparities in relation to the experience of disability are significantly understudied.

Without claiming to be representative, the collection of personal experiences and narratives is a particularly useful tool in giving voice to vulnerable groups, and in studying the processes that require the voices of those who experience them to be heard in order to be understood. In this context, the present study addresses the second objective of this thesis: *to explore the experience of mobility disability, inclusion and exclusion, as it is lived and expressed by individuals with mobility impairments in Romania.*

3.2. Method

11 people with mobility impairments (8 women, 3 men, ages 19–45 years, M_{age}= 28.27) were contacted through the Office for Students with Disabilities of Babeș-Bolyai University and through snowball sampling. The interviews were recorded using a voice recorder, with the verbally expressed consent of participants. An interpretative-phenomenological analysis (Smith, 1996, 2004) was conducted on the content of the transcriptions.

3.3. Results

Five main themes emerged from the data. The first theme, *feeling different*, indicates that while they were still acknowledging and adjusting to their physical impairments, participants' discourses were infused with social representations of disability as a medical problem and a personal tragedy, resulting in perceptions of their bodies as the sources of their status as "misfits" and "outliers". Under a lack of positive social discourses and models of independent living, the people with physical impairments we interviewed were left to discover for themselves that their individualities cannot be reduced to impairment. Within *reframing normality*, participants acknowledged their own capacities and had come to understand that the sick roles they are often socially expected to fulfill overlook their human qualities, their need to search for and fulfill meaningful goals in life, and their need to function within the world. However, in a context that constantly confronted them with the need to bridge the gaps between their bodies and unwelcoming social and built environments, participants described the process of carving their own trajectories in society as a one-person struggle.

The third theme, *perceived as a "different regnum"* suggests that besides isolating them visually, participants' bodies were perceived to be socially represented as grounds for their forced isolation into inferior, sick roles. Being pitied, being praised for insignificant achievements, being confronted with low expectations, and being addressed indirectly through their able-bodied companions also suggest representations of disability as a tragic illness, and perceptions of people with disabilities as childlike or inferior (Brisenden, 1989). Moreover, the fact that some people with mobility impairments were identified as beggars suggests representations of people with disabilities as “objects of charity” (Oliver, 1999). The disabled people we interviewed also often felt *confined by physical barriers*, as their bodies and assistive devices are not accommodated within the built environment, forcing them to rely on others for help. At the same time, responsible authorities and institutions were perceived to remain indifferent in practice, contrary to their overtly expressed preoccupation with accessibility.

Many of the negative attitudes that reduce people with disabilities to their impairments were traced back by participants to the former socialist regime within the *ghosts of the past and desires for the future* theme. However, their discourses also shaped directions for future changes. Through invoking disability as a part of the human condition and diversity, and through drawing attention to the social and structural barriers they experience in seeking to build independence and live “normal” lives, participants challenge medical understandings of disability and bring forth discourses similar to those promoted through the social model and the movement for independent living (Scotch, 1989).Furthermore, once again the narratives of people with disabilities emphasize the importance of their own roles in challenging segregative attitudes and practices within society.

3.4. Conclusions

While the legislation promises them protection from discrimination and unrestricted access to education, employment, and participation, the people with mobility impairments we interviewed described a reality where they are reduced to their “defective” bodies, segregated, and misunderstood as a result of negative social attitudes and architectural barriers. While participants managed to incorporate the impairments that were perceived to make them “different” as part of human diversity, social and architectural barriers seem to still widen and enforce negative values upon the “differences” between people with and without disabilities. This study highlights a pressing need for the discourses established by the social model of disability and the movement for independent living, and not only these, to be studied, understood, and adopted further within Romanian society and institutions. Furthermore, it suggests that the implementation of inclusion regulations needs to be much more rigorous. Finally, it is highlighted that disabled people have important roles to play in challenging negative attitudes and practices regarding disability and inclusion within society.

CHAPTER 4

Study 3: Attitudes towards Mobility Disability and Perceptions regarding Accessibility in a Romanian Sample

4.1. Introduction

Negative attitudes resulting from the medicalization of disability and pressures towards productivism hinder the implementation of inclusion policies and accessibility regulations in formerly socialist countries such as Romania, and not only (Phillips, 2012a, 2012b; Mladenov, 2015, 2017a; McLean et al., 2017). Furthermore, people with disabilities perceive that as a result of negative social attitudes, there is little practical concern regarding their inclusion and accessibility needs. Measuring attitudes is a key process in understanding social constructions of disability and finding targets for improvement (Palad et al., 2016). Evaluative cognitions, affective reactions and behavioral responses are interrelated and involved in both the formation and the expression of attitudes, to various degrees (Eagly & Chaiken, 2007). The use and refinement of multidimensional instruments that include all three components is encouraged, as is the investigation of relationships between different aspects of attitudes and socio-demographic, individual, and situational variables (Antonak & Livneh, 2000).

In this context, this study addresses the third objective of the present thesis, aiming *to study social attitudes towards mobility disability and social perceptions regarding how the built environment welcomes disabled people*. More specifically, we aim to (1) to validate an instrument measuring attitudes towards disability in a Romanian sample, (2) to investigate the attitudes towards mobility disability in a sample of nondisabled Romanians, and (3) to explore the relationship between attitudes towards mobility disability and perceptions regarding the accessibility of the built environment.

4.2. Method

Participants (200 women, 39 men) aged between 18 and 87 years old (M_{age}= 27.50) from different locations in Romania were recruited through e-mail and social media, using snowball sampling.

Attitudes towards disability were measured using the Multidimensional Attitudes Scale towards Persons with Disabilities (MAS, Findler, Vilchinsky, & Werner, 2007) revised by Vilchinsky, Werner, & Findler (2010). The 22-item questionnaire presents a vignette describing a casual social interaction between an able-bodied person and a person with a disability (a wheelchair user, in the present study), and a list of *emotions*, *cognitions*, and *behaviors* that the able-bodied individual might experience and perform in the hypothetical situation. Respondents are asked to rate the likelihood that the able-bodied character would experience each cognition, emotion, and perform each behavior, on a 5-item likert scale. Participants' answers are then coded into five subscales, distinguishing between *negative affect, interpersonal stress, calm, positive cognitions,* and *distancing behaviors*. Scores on the five subscales are obtained by computing the mean of relevant items, with larger scores indicating more *negative affect*, higher *interpersonal stress*, more *distancing behaviors*, more *calmness*, and more *positive cognitions*.

For the purpose of this study, we added three optional open-ended items to the MAS, inviting participants to “suggest and elaborate on other cognitions, emotions, and behaviors” that they believe one might experience or perform in the situation presented by the vignette. This was done in order to supplement quantitative data with qualitative insights that are potentially informative regarding social representations of and reactions to disability.

The *perceived accessibility of the built environment* was measured using an 81-item survey (Appendix 4.2.) constructed by the authors with the help of an architecture and urban planning expert.

The MAS was translated in Romanian by the authors (see Appendix 4.1.), and back to English by an independent translator. The MAS and the accessibility survey were distributed via social media, online messaging, and e-mail.

The present study employed mixed methods to investigate attitudes towards disability. After a confirmatory factor analysis was performed on the MAS, paired samples t-tests were used to investigate differences between the dimensions of attitudes and to identify which reactions to disability are more likely to occur in the hypothetical interaction with the wheelchair user. At the same time, content analysis was performed on the answers to the three optional open-ended questions regarding additional reactions to disability. Paired samples t-tests were also employed to investigate differences in the perceived accessibility of different environmental categories. Correlational analysis was performed to investigate relationships between attitudes towards disability and overall perceptions of accessibility.

4.3. Results

A confirmatory factor analysis (CFA) with the maximum likelihood procedure was performed using AMOS 20.0 (Arbuckle, 2011) to validate the five-factor structure of the MAS. After removing three items that failed to load on either factor, the resulting 19-item, five-factor model comprised of *negative affect*, *interpersonal stress*, *calm*, *positive cognitions*, and *distancing behaviors* provided a satisfactory fit (Byrne, 2010), as indicated by χ^2, χ^2/df values and goodness-of-fit statistics ($\chi2(142)=266.700$; CFI=.93, TLI=.92; IFI=.93; RMSEA=.061).

The results of the ten paired-sampled t-tests suggested that in an interaction with a wheelchair user, participants projected a nondisabled person would most likely experience *positive cognitions*. *Calm* was projected as less likely to be experienced than *positive* cognitions, and *negative affect* was rated as less likely than *calm,* but more likely than *interpersonal stress*. *Distancing behaviors* were rated as least likely to occur.

30 participants (27 women, 3 men, $M_{age}=30.23$) also completed the optional open-ended items added to the MAS. Some answers consisted of short phrases that detailed and merged cognitions, emotions, and behavioral intentions, and others simply listed emotional reactions such as “empathy” or “curiosity”. After performing content analysis, answers were clustered around three categories that were developed inductively, each highlighting different representations of disability and behavioral intentions across the approach-distancing spectrum. *Approach and equal treatment* includes stated beliefs that people with disabilities should be viewed as equal peers, and expressed behavioral intentions of approaching and interacting with the wheelchair user as such. Representations of the interaction as *an opportunity for “personal growth”* emerged from participant answers through curiosity towards perceived differences, through compassion towards another’s perceived suffering, and through genuine understanding. Some participants perceived the wheelchair user as

“suffering” or needing encouragement, while others were interested in their story, assuming it would revolve around disability and adjustment. At the same time, some participants stated that meeting disabled people in real life has made them see disability in a more positive light. The *Discomfort towards Differences* category includes answers focused on differences between the two interlocutors, and projected reactions of fear, ambivalence, discomfort, and covert avoidance. Some participants anticipated the able-bodied character would be “uncertain” or “initially fearful” to approach the wheelchair user. Other participants projected feelings of discomfort, pessimism, discouragement, and uncertainty into the interaction. Some of these participants also anticipated that the able-bodied person would make efforts to avoid paying visible attention to their interlocutor’s disability and/or their wheelchair, in order to regulate their own discomfort and to avoid making the other person feel uncomfortable as well.

In terms of how attitudes towards disability relate to perceptions of the built environment, high scores on both *positive cognitions* and *negative affect* were associated with perceptions of the built environment as more accessible. These results suggest two interesting hypotheses regarding implicit perceptions regarding disability and accessibility. *Negative affect* such as sadness, pity, and guilt is associated with perceptions of disability as an individual medical problem, and a personal tragedy (Oliver, 1986; Shapiro, 1993). Such representations tend to overlook the role of the environment in disablement, therefore may be associated with perceptions of the built environment as less problematic. There is evidence suggesting that positive cognitions towards disabled people may be employed to counteract the same implicit negative stereotypes towards disability that are associated with negative affect (Baumeister, Dale, & Sommer 1998). This might explain why both in the presence of *positive cognitions* and *negative affect*, the built environment would be perceived as less problematic. However, a second possibility is that *positive cognitions* are underpinned by representations of disabled people as likely social interlocutors, and reflect perceived positive changes in the inclusion of disabled people.

4.4. Conclusions

This study indicates that in an interaction with a wheelchair user, a nondisabled person would be most likely to experience *positive cognitions* and least likely to perform *distancing behaviors.* Furthermore, it suggests that some accessibility issues observed by people with disabilities are also perceived by nondisabled people. However, it is also highlighted that lack of familiarity, and representations of disability as an illness or tragedy still foster implicit negative reactions to disability that may permeate social interactions with disabled people, despite explicit and conscious regulation attempts. Because negative attitudes function both as predictors and as outcomes of the implementation of inclusion and accessibility regulations, these findings stress the need to further promote attitude changes at a social and institutional level. Most importantly, disability must be differentiated from *impairment,* and the role of the environment in shaping *disability as a human condition* must be acknowledged, in order for more realistic and welcoming understandings of disability to permeate society.

CHAPTER 5

5.1. Study 4.1: The structure of the COPE questionnaire on a Romanian sample of people with mobility impairments

5.1.1. Introduction

Coping is considered by the ICF to be one of the personal factors that shape the experience of disability (WHO, 2001), often mediating the relationship between health and environmental factors on one hand, and psychosocial outcomes on the other hand (Martz, Livneh, & Wright, 2007). A number of personal resources are shown to guide the selection of coping strategies when living with chronic illness and disability. Higher levels of self-efficacy and sense of coherence are both associated with greater allocation of resources and efforts in achieving desired outcomes, and with more reliance on active, problem-solving coping strategies (De Ridder & Schreurs, 1996; Kemp, Morley, Anderson, 1999; Lustig, 2005). People with disabilities in Romania face a number on significant challenges and disparities relevant to their participation, inclusion, and psychosocial wellbeing, stemming from negative social attitudes towards disability. However, little is known regarding the personal resources and coping strategies employed in relation to the experience of living with a disability in Romania, and the environmental challenges that shape it.

The COPE questionnaire was developed by Carver, Scheier, & Weintraub (1989). While it has been previously translated and validated on Romanian samples (Băban ,1998, p. 113-119; Crașovan & Sava, 2013), to the extent of the authors' knowledge, it has not been previously used on a sample of Romanians with mobility impairment. Furthermore, its structure is difficult to replicate, with results varying across samples (Eisengart et al., 2006; Kato, 2013; Crașovan & Sava 2013). In this context, this study aims to explore the factorial structure of the COPE questionnaire on a sample of Romanian adults with physical impairments and to to examine its criterion-related validity by investigating the relationship between coping strategies and time since living with a disability, disability severity, self-efficacy, sense of coherence, perceived physical/ structural and attitude/ support barriers, and psychosocial adjustment.

Based on the relevant literature regarding the relationship of different coping styles with personal resources and psychosocial outcomes in living with a disability, it was hypothesized that: (1) A higher use of approach coping strategies would correlate with higher levels of self-efficacy and sense of coherence, and with less reported psychosocial adjustment difficulties, and (2) A higher use of disengagement coping strategies would correlate with lower self-efficacy, a lower sense of coherence, and poorer psychosocial adjustment.

Because the selection and usefulness of different coping strategies vary greatly as a function of intensity, duration, and perceived controllability of a stressor (i.e. disability), no specific hypotheses regarding the relationship between coping strategies and disability severity or time since living with a disability were formulated. Furthermore, because both active/ approach and avoidant / disengagement coping strategies are considered as plausible coping responses to environmental barriers in the presence of functional limitations (Tomey & Sowers, 2009), no specific hypotheses were developed regarding the relationship between coping strategies and perceived physical/ structural and attitude/ support barriers.

5.1.2. Method

Participants (N=97, M_{age}= 45,6) were recruited through the help of the General Direction for Social Assistance and Protection of Children and People with Handicap of Cluj-Napoca, the Cluj-Napoca Community Center, the Medical Clinic II of Cluj-Napoca, the Society for the Handicapped of Zalau, and through snowball sampling. Questionnaires were distributed in printed form by the researchers, and through the personnel of the abovementioned institutions. Participants completed the questionnaires during their visits.

Coping strategies were assessed using COPE (Carver, Scheier, & Weintraub, 1989), which has been translated to Romanian by Băban (1998, p. 113-119) and Crașovan & Sava (2013).

Disability severity was measured using the WHO Disability Assessment Schedule, WHODAS 2.0 (WHO, 2010).

Self-efficacy was measured using the Generalized Self-Efficacy Scale (Schwarzer & Jerusalem, 1995), which has been translated in Romanian (Băban, 1998, p. 113-119; Vasiliu, Marinescu, Marinescu, & Rizeanu, 2015a).

Sense of coherence was measured using Antonovsky's SOC-29 (Antonovsky, 1987), which was translated in over 20 languages, including Romanian (Băban, 1998, p. 113-119; Vasiliu, Marinescu, Marinescu, & Rizeanu, 2015b).

Physical / structural and attitude / support barriers were assessed using the Craig Hospital Inventory of Environmental Factors (CHIEF, Whiteneck et al, 2004a).

Psychosocial adjustment to disability was assessed using the self-report version of the Psychosocial Adjustment to Illness Scale (PAIS-SR, Derogatis, 1986).

5.1.3. Results

An exploratory factor analysis (principal axis factoring) with promax rotation was performed on COPE's 60 items. The Kaiser-Meyer-Olkin measure of sampling adequacy was .70, while the Bartlett's Test of Sphericity was significant, indicating that proceeding with a factor analysis was acceptable. An oblique rotation was chosen, as factors were expected to be correlated. The unconstrained principal axis factoring indicated 10 eigenvalues >1.

The Scree plot showed a distinct break off after the fourth factor, and parallel analysis also suggested the retention of only four factors. The principal axis factoring procedure was repeated constraining the extraction to four factors. Following the recommendations of Floyd and Widaman (1995), and Stevens (2003, as cited in Habing, 2003), items with loadings lower than .5 and cross loadings higher than .3 were eliminated, resulting in a solution comprised of 35 items that load onto 4 factors, explaining 48.8% of variance: *approach coping*, *disengagement coping*, *humor*, and *substance use*. Factor scores were saved using the regression method. Approach coping includes items originally assigned by Carver, Scheier, and Weintraub (1989) to the *active coping, planning, restraint, suppression of competing activities*, and *positive reinterpretation and growth* subscales. Disengagement coping comprises items from *denial*, *focus on and venting of emotions*, and *behavioral disengagement*.

Correlational analyses employed to investigate the criterion validity of the COPE indicated that higher levels of approach coping were associated with higher levels of self-efficacy and sense of coherence, partially confirming the first hypothesis. A small but significant correlation indicated a more frequent use of approach coping is associated with less reported psychosocial adjustment difficulties. A small negative correlation between the use of approach coping and time since living with a disability was also observed. A higher use of disengagement coping was associated with a lower sense of coherence, poorer psychosocial adjustment, and more perceived physical/structural and attitudes/ support barriers, partially confirming the second hypothesis. Substance use was associated with more perceived attitudes/support barriers. There were no significant relationships between disability severity and the use of different coping strategies.

5.1.4. Conclusions

The exploratory factor analysis of the COPE questionnaire indicated a four-factor model of coping, comprised by approach coping, disengagement coping, substance use, and humor. This builds on previous evidence showing that various items assigned to active coping, planning, restraint, suppression of competing activities, acceptance, and positive reinterpretation and growth tend to collapse into a single factor (Kimemia, Asner-Self, & Daire, 2011; Snell et al, 2011), while *denial, focus on and venting of emotions,* and *behavioral disengagement* were initially identified as part of the same cluster of strategies focused on distancing oneself from the problem or the associated emotional distress (Carver, Scheier, & Weintraub, 1989). Correlation analyses investigating the criterion-related validity of the COPE's structure partially confirmed both hypotheses of the present study, and build upon previous research indicating that high levels of self-efficacy and sense of coherence are associated with more use of approach coping strategies, while disengagement coping strategies are associated with poorer psychosocial outcomes. These findings invite further investigations regarding the structure of coping in living with a disability, and its roles regarding the psychosocial adjustment and the wellbeing of disabled people in Romania.

5.2. Study 4.2.: Personal factors, environmental perceptions and psychosocial adjustment and functioning in a Romanian sample with physical disabilities

5.2.1. Introduction

The International Classification of Functioning (ICF, WHO, 2001) describes a set of complex interactions between health conditions, personal, and environmental factors, which in turn affect body functioning and structures, and the person's activities and participation, resulting in disability. Personal factors that shape disability and psychosocial outcomes in living with a disability may vary greatly across cultures, and range from demographics such as age, gender, and race, to life habits, and coping styles (WHO, 2001; Martz, Livneh, & Wright, 2007). Other personal resources that have been linked to wellbeing, perceptions of health, and performance of self-management and health-promoting behaviors in people with disabilities are self-efficacy and sense of coherence (Martz, Livneh, & Wright, 2007; Hampton, 2004; Marks & Allegrante, 2005; Eriksson & Lindström, 2006; Middleton, Tran, & Craig, 2007). Self-efficacy and sense of coherence have also been shown to guide the selection of coping strategies, and are associated with a stronger preference towards active, approach coping strategies (Martz, Livneh, & Wright, 2007). Environmental factors that shape disability and impact psychosocial outcomes in living with a disability include social components such as attitudes towards disability, support, assistance, discrimination, and structural factors such as accessibility.

In the context of significant contrasts between what the inclusion and accessibility legislation stipulates on the one hand, and the documented reality and perceptions of people with disabilities on the other hand, an investigation of how personal factors and perceived environmental barriers relate to disability and psychosocial adjustment could be helpful in promoting a better understanding of the experience of disability in Romania, in drawing attention to important barriers disabled people encounter, and in informing future inclusion efforts. The present study addresses the fourth objective of the present thesis, by aiming *to investigate how environmental* (social and structural environmental perceptions), *and personal factors* (age, time since living with a disability, self-efficacy, sense of coherence, and approach / disengagement coping strategies) *relate to experienced disability and psychosocial adjustment in a Romanian sample of people with mobility impairments*.

5.2.2. *Method*

Participants (N=97, M_{age}= 45,6) were recruited with the help of the General Direction for Social Assistance and Protection of Children and People with Handicap of Cluj-Napoca, the Cluj-Napoca Community Center, the Medical Clinic II of Cluj-Napoca, the Society for the Handicapped of Zalau, and through snowball sampling. Questionnaires were distributed in printed form by the researchers and through the personnel, and were completed by participants during their visits at the abovementioned institutions.

Disability was assessed using the WHO Disability Assessment Schedule – WHODAS 2.0 (WHO, 2010).

Self-Efficacy was measured using the General Self Efficacy Scale (Schwarzer & Jerusalem, 1995), translated in Romanian by Băban (1998, p. 113-119) and Vasiliu et al (2015a).

Sense of Coherence was measured using SOC-29 (Antonovsky, 1987), which was translated and used in over 20 languages, including Romanian (Băban, 1998, p. 113-119; Vasiliu et al, 2015b).

Coping strategies were assessed using COPE (Carver, Scheier, & Weintraub, 1989), which has been translated to Romanian by Băban (1998, p. 113-119), and Crașovan & Sava (2013). The structure of the COPE was examined in study 4.1. (Chapter 5, section 5.1.).

Psychosocial adjustment to living with a disability was assessed using the Self-Report version of the Psychosocial Adjustment to Illness Scale (PAIS-SR, Derogatis, 1986).

5.2.3. Results

Structural equation modeling (SEM) was employed in order to investigate how age, time since living with a disability, self-efficacy, sense of coherence, approach and disengagement coping strategies, and physical / structural and attitude / support environmental perceptions relate to psychosocial adjustment and disability. Results indicated that a lower sense of coherence and more perceived physical / structural barriers were associated with a higher use of disengagement coping. More perceived structural barriers were also associated with more severe experienced disability. Lower self-efficacy, a higher use of disengagement coping, more perceived attitude / support barriers, more advanced age, and more severe experienced disability were associated with poorer psychosocial adjustment, and explained 60% of its total variance. The final model presented adequate fit indices, with $\chi 2(10) = 14.29$, $N = 97$, $p = .16$; CFI = .97; TLI = .94; IFI = .98; RMSEA = 0.67.

5.2.4. Conclusions

These results build upon previous evidence indicating that self-efficacy is associated with higher wellbeing and better health outcomes in living with chronic illness and disabilities (Marks & Allegrante, 2005; Martz, Livneh, & Wright, 2007). They also reflect existing findings regarding the role of social attitudes and support in the quality of life and psychosocial adjustment of people with disabilities (Goreczny, Bender, Caruso, & Feinstein, 2011). While a higher use of disengagement coping was associated with poorer psychosocial adjustment, there was no significant relationship between approach coping strategies and disability or psychosocial adjustment to disability. On the one hand, these findings reflect previous evidence that disengagement coping strategies are associated with poorer psychosocial outcomes (Chan & Heck, 2000; Kennedy, Lude & Taylor, 2006; Martz, Livneh, & Wright, 2007; Craig, Tran & Middleton, 2009). On the other hand, approach coping was also found to be unrelated to psychosocial outcomes in living with disability or a chronic illness in a few previous studies (Shen, McCreary, & Myers, 2004; Wineman, Durand & Steiner, 1994)

The fact that more perceived physical / structural barriers were associated with more experienced disability expands on the extensive existing literature documenting the disabling role of the built environment (WHO, 2001; Hammel et al, 2015; Barclay, McDonald & Lentin, 2015). The fact that more perceived physical / structural barriers and a lower sense of coherence were associated with a higher use of disengagement coping suggests that disengagement coping strategies are employed in attempts to manage emotional distress in the presence of stressors (in this case, environmental barriers) that are perceived to be unchangeable and uncontrollable by the individual (Martz, Livneh, & Wright, 2007). These findings also support previous evidence that sense of coherence guides the selection of coping strategies regarding disability-related challenges (Martz, Livneh, & Wright, 2007; Chevalier, Kennedy & Sherlock, 2009).

CHAPTER 6.

General Discussion and Conclusions

In the past decades conceptualizations of disability have evolved to acknowledge the importance of the social and built environment in creating disability. After the fall of the communist regime and in the light of these developments, Romania joined international efforts regarding the inclusion of people with disabilities. However, available research indicates some significant differences between what inclusion legislation and accessibility regulations stipulate, and actual changes in practice. At the same time, the presence and voices of disabled people in terms of sharing their experiences, tackling inclusion issues, participating in disability rights activism, and shaping social understandings of disability are all but unheard.

The present thesis investigated the social understandings and experiences of disability and inclusion within the Romanian context. Our findings indicate that the experience of living with a mobility disability in Romania is riddled with contrasts between the needs of disabled people and the reality they perceive on the one hand, and between how disabled people experience disability and how they are socially perceived, on the other hand. Furthermore, they bring forth the role of social and structural environmental factors in shaping disability, while highlighting resources such as self-efficacy and sense of coherence in adjusting to disability. The present thesis indicates that changes regarding the approach of disability have focused on legislation and regulations, but have not addressed deeper issues regarding the general understanding, evaluation, and attitudes towards disability in social and institutional settings. Still-standing medical and productivist understandings of disability define it as a personal, medical issue that prevents individuals from actively participating in society, overlooking the role of environmental factors in disablement is overlooked. Consequently, responsibility and interest regarding inclusion from society and institutions is decreased, while the responsibility to "rehabilitate" and "reintegrate" is placed mostly on disabled people. This also creates discrepancies between what the inclusion and accessibility legislation stipulates and the social and physical reality experienced by people with disabilities, where the legislation is superficially respected and the utility behind accessibility regulations is not understood. However, the representations of disability shared by people with mobility impairments validate the social model and the movement towards independent living as being faithful to their lived experiences, even in the near absence of such discourses in mainstream media and society. Furthermore, through sharing their experiences disabled people acknowledge their own role challenging negative social representations of disability and defending their rights in regards to accessibility.

6.1. Limitations and future research directions

It is possible that the experiences presented within this research are not representative for all people with mobility impairments. This opens the opportunity for future research to focus on more specific aspects of how people with different disabilities interact with various domains such as healthcare, education, and employment. Furthermore, the modest sample sizes invite further investigation regarding the factorial structures of the MAS and COPE questionnaires in order to verify the generalizability of the present findings. Finally, longitudinal studies could offer more information regarding the outcomes associated with different resources and coping strategies in living with a disability.

6.2. Original contributions of the studies

The present thesis brings forth the less heard voices and discourses of disabled people in Romania in challenging problematic aspects regarding inclusion, accessibility, and mainstream perceptions of disability. It offers a historical and theoretical framework for the discrepancies between inclusion legislation and practice, highlighting that the medical-productivist understandings of disability still undermine inclusion efforts and prevent from alternative understandings of disability to permeate society and institutions. At the same time, it brings forth alternative discourses, such as the social model, that could be useful in offering a better understanding of disability. Furthermore, this thesis presents a translation and validation of the structure of the Multidimensional Attitudes Scale towards persons with disabilities (MAS), an instrument that can be used to further investigate attitudes towards disability in Romania, and an investigation of the structure of the COPE inventory as it was first used, to the extent of the authors’ knowledge, on a sample of disabled people in Romania. Finally, this thesis presents an insight into how personal factors and environmental perceptions may relate to disability and psychosocial adjustment in a sample of Romanians with mobility impairments.

6.3. Implications of the studies

The present thesis draws attention upon specific social and structural barriers experienced by people with disabilities, highlighting the need for improving social attitudes towards disability, and a more thorough implementation of inclusion and accessibility laws and regulations. It highlights that restrictive medical-productivist social understandings of disability must be overcome, as they remove responsibility and decrease interest from society and the relevant authorities in making effective changes in practice. Our findings stress that in order to create a social context of inclusion and social responsibility, the understanding of disability as a part of human experience and diversity that is greatly shaped by the built and social environment is required to permeate medical, legislative, educational, work, and mass media settings, and guide the development and implementation of social services, social policies, legislation, and regulations regarding inclusion and accessibility. The social model, the movement for independent living, and the discourses of disabled people brought forth within this thesis could inform future educational efforts and programs directed at attitudinal change in various domains, institutions, and services that people with disabilities interact with. Finally, this thesis highlights the need for self-empowerment for disabled people, so that they become active and involved in the changes the need in order to live full lives.

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