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SPECIAL ISSUE

FOGYATÉKOSSÁG ÉS TÁRSADALOM

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ELTE Bárczi Gusztáv Faculty of Special Needs Education

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Tímea Vissi

'Hello, I am here!'

Psycho-Emotional Disablism in the Life Stories of People with Disabilities

INTRODUCTION

This study is a secondary analysis in which data was gained from a more extensive research study. While the earlier study focused on factors *promoting* inclusion from the perspective of people with disabilities, this study targets secondary data analysis corresponding to with Reeve's concept (2012, 2004, 2002) of psycho-emotional disablism. Consequently, although critical elements are presented, I intend to emphasise that the focus of interest remains letting the participants' voices be heard rather than analysing the Norwegian system and disability policy.

In this study six semi-structured life-story interviews, one semi-structured focus group interview and a field diary on a 34-hour participant observation (with seven participants) were subject to analysis. The data collection took place in two Norwegian towns in October and November 2019. As the persons involved would be easily recognisable by determining the exact locations, these are omitted with the mutual consent of the research participants, to ensure anonymity. The typing of the interviews took place in December 2019 followed by the primary qualitative analysis according to the grounded theory method in January and February 2020 and the secondary data analysis in April and May 2020.

The research participants were young adults (aged 26 to 34) with cerebral palsy (CP). In contrast to the general Hungarian term of mobility impairment based on the medical model, I regard CP rather as a complex disability, a term that has recently become widespread in the international literature, which refers to the heterogeneity of persons with CP more precisely. Consistent with the term 'complex disability', the persons involved are people with complex needs.

I approach disabilities from a critical disability studies (CDS) perspective that reconsiders normality, emphasises the complexity of disabilities, and questions 'the unbodied, standardised, rooted and liberal-humanist concept of identity and works with the concept of a decentralised, embodied subject being in a constant state of becoming someone or something' (Antal et al., 2018, 85). Disability Studies, as a discipline, differentiates between *impairment* and *disability* by stressing, in line with the perception of strong social criticism, that disability is a social construction, a negative social reaction to impairment that consequently creates the definition of the 'other', referring to something that deviates from the 'normal' (Goodley 2017; Wendell, 2010). Disablism refers to a situation in which people are subject to social exclusion, preventing them from being full participants in society (Goodley, 2017, 11).

1. The theoretical framework of this study

In critical DS, the social model of disability is considered insufficient for any understanding of the complexity of a disability, as it places emphasis on socio-cultural barriers but disregards the personal dimensions of disability (Reeve, 2004, 2002). Reeve develops Thomas's recommendation (1999), according to which the experience of disability has a psycho-emotional dimension, in that it influences the psycho-emotional well-being of people with disabilities.

> *'Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being' (Thomas, 1999, 60).*

Reeve extends the social model (Reeve, 2012, 2004, 2002) which consists of both structural and psycho-emotional dimensions of disability. He has a progressive concept that focuses on 'what people with disabilities are able to become' instead of 'what they are actually capable of'. She distinguishes between direct and indirect disablism and scrutinises their impact on psycho-emotional well-being.

1.1. Indirect disablism: structural disability

People with disabilities experience physical barriers and social exclusion in their everyday lives. These consist of segregated education, inaccessible buildings and separate entrances for people with wheelchairs, which not only restrict or separate them physically, but also imply that 'you are different, you do not belong to us'. This type of experience provokes various emotions in people with disabilities, such as anger, shame, disappointment, anxiety, desperation, sadness and resignation, in turn affecting their psycho-emotional well-being, self-concept, self-esteem and self-confidence, and, hence, *making them disabled in an indirect way* (Reeve, 2014, 2012, 2004).

The main difference between people living with disabilities and other minorities is that it would be completely inconceivable in the Western hemisphere in the 21st century to have separate access to a building for any minorities. However, people with disabilities face this on a daily basis. It reinforces the feeling of being second-class citizens, and that their presence is nothing more but tolerated. The emotional message of physical exclusion is the manifestation of psycho-emotional disablism, which increases the oppressive nature of structural disability (Reeve, 2004).

1.2. Direct disablism: interaction with others

People with disabilities often have painful, humiliating experiences during social interaction with others. Disablism may appear in social interaction in various forms, such as jokes about their condition, avoidance or even open rejection. It is also frequent that they receive unrequired opinions addressed directly to them (e.g. 'they would rather die instead of living like this') or by muttering something about them when passing by (Reeve, 2012).

People living with disabilities must face the fact that their bodies are objectified or examined only for the purpose of listing their defects, be it during a medical examination or in social schemes where their entitlement to benefits is to be decided upon. This results not only in feeding their sense of being 'other' but also in nurturing the feeling of being fragile and vulnerable and that their bodies are something to feel ashamed of.

One reason for disablism is that there are no culturally accepted rules regulating how strangers should make contact with people with disabilities. This has been regarded as a concern not only in relation to people with disabilities, though, but also to everyone whose body differs from the required and desired body in any way. As much as we tend to express our appreciation of a slim, 'perfect' body in a culturally accepted way by demonstrating our positive attitude ('You look pretty!', or 'These trousers suit you very well!'), we have difficulties with such observations when meeting someone who has put on weight (Reeve, 2014).

A highly ruinous effect of psycho-emotional disablism occurs when a person with disabilities internalises negative social stereotypes and prejudices, which Reeve (2004, 2012, 2014) describes as internalised oppression. This form of oppression often affects self-esteem on a subconscious level, which also shapes the person's attitudes and actions. It may create false consciousness if, for example, a person with disabilities believes that people like them cannot have an intimate relationship or have children. It may also result in creating double consciousness in which a person with disabilities lives with the constant knowledge of being 'other', living as an alien in the world. They can accept the stereotype that people with disabilities are not 'perfect' and that they are less valued than able-bodied people (Reeve, 2012).

2. RESEARCH METHODS

The following qualitative methods were applied: life-story interviews, participant observation, and a semi-structured focus group interview. The participants were recruited via email and a written information sheet had also been sent in advance. Before their informed consent was obtained, an oral presentation was organised, in which all the participants were given an opportunity to inquire about the details. Seven persons (three women, four men) aged 26–34, with complex disabilities and diverse support needs were involved in this study (one only agreed to participate in the participant observation) and five parents or personal assistants took part in the focus group interview. Participation was voluntary and anonymous.

The various methods offered access to different 'data', although the primary aim was to remain focused on the personal opinions and experiences of the persons with disabilities. Therefore, we led conversations during the participant observation and they regularly commented on the ongoing activity, their remarks being recorded either at the same time, or, due to time constraints, immediately after finishing the observation. The research documentation was extended with a research diary presenting a detailed description of the events, dates and persons involved, as well as my impressions, thoughts and dilemmas including possible solutions as well as my decisions with a brief reasoning.

The language of the interviews and conversations was English, being a second language for both the participants and me. I had a basic level of Norwegian which

proved to be sufficient in overcoming language barriers. For instance, when the participants changed from English into Norwegian, I could understand and record it both at the time and later in the typing, but they were asked politely to use English. The research was carried out in compliance with the ethical permission regulation *SE PAK 1/2019.10.15*.

3. RESULTS

Due to the volume limitations of this article not all the participants' quotes are selected. The study focuses on the most mentioned and most frequently occurring experiences. I chose those sections of the field diary in which the participants described their experiences in relation to the observation, as I intended to emphasise that their opinions and explanations were the centre of interest.

The participants form a small and, therefore, easily identifiable group. Discussing and agreeing with participants to ensure anonymity, any citations were removed that referred to events and data and that would thus make it easier to identify them. Likewise, names of places, organisations and persons were deleted. For the same reason, the participants' gender, age or other characteristics are not indicated.

3.1. Indirect disablism

In the analysis, not only are the barriers of the built environment or exact forms of exclusion as indirect disablism classified, but also *all human-built environmental factors*, including the role of tools and the issue of personal assistance needed for overcoming physical disability.

Environmental barriers often promote the physical exclusion of people with disabilities from buildings, events, and, in an indirect way, from everyday social life.

> *'The environment of course is really important in independent living as well, as another thing, because […] yes, for example, if you have any equipment or wheelchair or […]. It's, it's really important the environment around you can be accessible and available for everyone. We still have a long way to go when it comes true that people with disability take part in the same life as anyone else.'*

Although Norway seeks to eliminate structural obstacles, and in my own experience it has been a pioneer, the participants complained about stairs, lifts that were not wide enough, and doors which were not at all or not easily accessible with wheelchairs, all of which I have also experienced. The participants also mentioned obstacles concerning theatres and cinemas, where there was space in the auditorium for people with wheelchairs, but electric ones did not fit into the lift, so audience members with electric wheelchairs could not arrive at the auditorium. Another concern was that there was room for only one wheelchair in the place of two chairs. The interviewee's concern was not so much that there was not enough room for two chairs but that the staff did not know what to do and so did not do anything to address the situation.

In all the Scandinavian countries, including Norway, the concept of normalisation was introduced in the 1950s, highlighting the importance of creating living conditions

for people with disabilities which resemble general life circumstances to the greatest possible extent (Lányiné Engelmayer, 1993). An ideological and political change was implemented concerning approaches to disability in Norway by the end of 1960s, which was consequently enacted in legislation. It became generally accepted that family support and day-time services should be strengthened rather than entirely supporting institutions. Reform and development of long-stay residential institutions was of major importance, and they focused on welfare measures to improve the quality of life of people with disabilities. By the 1970s the importance of environmental effects in relation to disability became the dominant view in Norway (Tøssebro, 2016), and has since become an important element of the Nordic Relational Model of Disability (NRM). The NRM was developed in the late 1990s and early 2000s, and it describes three main aspects of which 'disability is a person-environment mismatch, situational (contextual) and relative' (Jackson, 2018).

Although the NRM is a 'weak version of the environmental turn' (Tøssebro, 2004), and pays less attention to the man-made environment than to the social model of disability, the actions of UK activists had a major influence on the Norwegian disability concept in the Millennium years, which came to appear in the legislation. The Norwegian legislature approved the act on discrimination and the right to equal access in 2008 (Lag [Law] 2008), according to which all forms of discrimination were declared forbidden. Critics have blamed this change for being slow, and have urged the elaboration of solutions to new challenges; they realise that the mere adoption of welfare measures has not been sufficient. Difficulties arise elsewhere than in the welfare sector; if people with wheelchairs do not go to restaurants, the owners will not be confronted with the demand for stairs to be removed (Tøssebro, 2016).

> *'I'm using wheelchair and the experience is really often I can't go inside some building or some café, for example theatre, just because I am wheelchair-user. And this is a great issue.'*

None of the participants mentioned structural obstacles in education, which would have prevented them from taking part in classes, mutual programmes or otherwise connecting with their schoolmates. At nursery or school, they all had a personal assistant for a shorter or longer period of time who helped them getting from one point to the other and assisted them with the learning.

> *'I have not learning skills problem, I could learn, but I needed help. I didn't write, so to do my homework I needed an assistance's help.'*

They were provided with assistance tools in schooling, which, however, had not always been satisfactory in keeping up with their schoolmates. Nonetheless, technical development also had an impact on the development of assistance tools, and the improvement of computer systems in particular finally brought about radical change in their education.

> *'– And did you use a computer there or a tablet, ok, not a tablet because there wasn't a tablet at that time, but a laptop? Or maybe other devices to help you learn?*
> *– Yeah. But it was very slow. Because I used the joystick to use the computer.*
> *– So… you had to choose the letter you wanted to write with a joystick?*
> *– Yeah. It was too … it took one hour.*

– That slow. [Laughing]
– But when I was 14 or 15, I had this eye-tracking computer. Yeah, I deal, I could start to do my thing on the computer, here, on a normal screen! So, it was a… it was a turning-point, I think.'

There are some critical voices concerning inclusive education in Norway. Although 86 per cent of children with disabilities attend regular schools, 57 per cent of them learn under segregated circumstances for a certain period of time even in regular schools, which reduces social interaction and results in their exclusion from school communities (Finnvold, 2018). The research participants, with one exception, shared the same experiences as I did, although most of them regard them as learning assistance rather than exclusion.

> *'During my life, the social connections … uhm… uhm… during nursery school, there weren't so many problems with these things. But during my first years at school it was not so easy, because … at the beginning there are many, many teachers, they thought that I needed one-to-one schooling, so many times they took me out of the classroom. So, I couldn't interact very much with the others...'*

> *'– I remember uhm…, uhm… in primary school, there was one teacher who always took me out of the school. Oh, not from the school, from the class.*
> *– And teach you face-to-face?*
> *– Yeah, yeah.'*

> *'I was really slow, you know. So, I had to learn and learn and learn to read faster. It was hard… there was a teacher, she took me out, because we had a course. Do you know, it's a course to… to learn to read faster.'*

Welfare measures provide concrete results. The participants live in their own apartments, six of them in specially designed ones, where they can lead independent lives with some personal assistance. At the time of the building construction, the individual needs of the buyers were taken into consideration in accordance with which living conditions were set. Only one participant complained about living issues and was planning to move to a barrier-free environment.

> *'[…] Then in my home now, I live on the 3rd floor, with stairs, and carrying my groceries up in my hand, it's like…, it's heavy.'*

Many of them mentioned that having an accessible apartment alone is not sufficient for leading an independent life, and they also need personal assistance.

> *'I can say one thing about the BPA It says, it's independent life, and the assistants are the people's hands and eyes in that they can't do it by themselves. It's an important thing.' [in Norwegian: brukertstyrt personlig assistance; in English: user controlled personal assistance].*

> *Determining the weekly hours of personal assistance is a task of local government. The BPA-system (HUMANA) allows persons with disabilities to hire the assistants and to specify the volume and exact period of personal support to tailor the service to their real needs. The BPA plays a major role in their lives, not only when shaping their independent life and equal living conditions, but also in independent decision making, individual choice and*

controlling their own lives. It allows people with intellectual disability to take part in relevant discussions on themselves and to be ensured supported decision making.

'[… name] attends meetings with his assistants and his mother. He is not excluded from meetings. So, the BPA means that he has a lot of influence in what he would like to do, basically.'

There is are considerable differences in how many hours of assistance a person may be entitled to, which does not necessarily correlate with their needs.

'We live in a tiny little place with a very small local government and we get less support. For [… name] eighteen and a half hours of assistance are stipulated, but there's no assistant, so he doesn't get any assistance, while [… another name] is entitled to eighty hours and de facto receives it.'

'This is a special system in Norway. There is difference between the local communities, there are […] some places where you get everything you want. [In] Other places, you have nothing.'

The situation of those living in group homes raises even greater concerns, partly due to the increasing importance of parents who welcome full deinstitutionalisation (Tøssebro & Lundeby 2006), and partly due to the fact that, in accordance with Norwegian political values, a government decision was passed on the closure of large institutions in 1988, which was implemented between 1991 and 1995. This rendered Norway the first country in the world where all such institutions were closed. Those whose independent life required assistance were relocated in apartments within group homes with personal care facilities. These apartments include the residents' own bed- and bathrooms in buildings with a maximum of three to five such apartments in a residential neighbourhood (Tøssebro, 2016). The assistants who are employed in these apartments provide support for all the residents of the building. Although BPA regulations vary from county to county, according to the interviews people living in group homes are in a disadvantageous position irrespective of their place of residence, and the support provided caters to their care needs at the expense of their other needs.

'I know a couple in the middle of Norway who have a son with very many problems. He has only two hours a week. He hasn't any more. I think he's 42 years old.'

'I think that if the person with a disability has parents that are willing to fight for their child's needs, the person has a very nice life, but if they don't have parents who are able to fight, or if the parents have passed away… I don't know… they get help, but …. how much will be the minimum.'

3.2. Direct disablism: interaction with other people

Direct disablism takes various forms and can be highly damaging to a person's psycho-emotional wellbeing, as it can divert people from achieving their own potential (Reeve 2002). The research participants have been confronted with this type of disablism several times and the conversations and the participant observation showed that the effects of this disablism have been more significant, and the given emotional reactions have been strong with long-lasting consequences on the lives of people with disabilities.

In their early childhood the participants did not experience any peer rejection or discrimination, or at least, they could not recall any. This does not mean that they had positive relationships with their peers. Due to the fact that they all had personal assistants, many of them said that they had not made friends with other children, as it had been much easier to talk to the supporting adult.

> 'They used to run away from me. Run faster than me. I was not able to keep up with them, or to follow them. I used to play with my assistant at the beginning.'

Later, at school everyone but one participant was segregated from the class and educated separately for a shorter or longer period. This significantly reduced the chance of peer interaction. According to some research, exclusion emerges at school age and intensifies with age (Finnvold 2018).

> 'And in school time, when I was 12 to 15 years old, I was not so included in the others' activities. Because I always was inside when they went outside, so school time wasn't very good… But when I was in the secondary school, I was very included again. So it was a little bit up-and-down in school time.'

> 'In the first years it was OK, it was a normal relationship. But the other kids, uhm…, when we were a little bit older, like up to 10, I lost all contact with them.
> – All contact?
> – Yeah. Only in school, of course, but… there was a kid who was interested in me, he talked to me… it was really good. The girls laughed at me… so I was alone, when I was 11 or 12. Until I moved to [… place name] when I was 16. Yes, I was a bit lonely then.'

> '[…] Yes. In the secondary school. We were planning to go to uhmmm…. to uhm…. a trip to get to know each other… So, our teacher planned to take a trip to the top of the mountains in [… place name], where we'd sleep in tents, or something. I couldn't walk so much! And my father went to the teacher, and had a long talk with her, and told her that I had CP, that I could walk a limited distance, I was still a member of the class. […] And they had a long talk, and the next day, the teacher came to the classroom and said: "Oh, we can't go on the trip together, because one of you can't walk." So fuck! So we had to stay in the school, a pretty nice evening in the classroom with pizza and soda.
> – And the other kids? They liked it?
> – No [laughing], absolutely not. I was excluded from activities and social activities in class for the next three years.

People with disabilities not only experience exclusion in their childhood, but it may also occur as an obstacle with regard to their employment. In the quote below, the interviewee emphasises that merely creating an adequate physical environment is not enough.

> *'The attitudes… it shows in many ways that people can't work with positive environmental conditions alone. But also, if a disabled person applies for a job, they do not get a chance, all because we are in a wheelchair. So, for this reason, I think it is not anything special for Norway, it's like the whole of Europe and we wouldn't like to see it in Norway and in Scandinavia because our goal is good inclusion and integration.'*

One participant reported regular school abuse which culminated in causing psychological and physical symptoms. The abuse persisted for years and the school was unable to control the situation, so that only moving and changing school could ultimately stop it.

As stated in various studies, there is a strong correlation between violence, abuse, and disability (Hanisch, 2013; Hughes et al., 2012). Based on Hanisch's (2013) study, children with disabilities become victims of abuse and violence in Norwegian schools twice as often as their peers.

> *'And then the bullying started, the class… this student was jealous of me, and… I didn't want it, I just wanted to be like everyone else I had to, uhm…, so they said: "Why are you so lucky? No one cares about you, you are so stupid!"'*

> *'[...] And from the 6th class to the 10th class, I had no friends and I got emails, which said "you're terrible".'*

Attitudes, stereotypes, and the requirements created by teachers towards children with disability strongly affect the entire group of minors. Firstly, if they do not endeavour to involve these young people in activities, the group will follow this behaviour. (Finnvold, 2018). Secondly, low demands may transmit negative stereotypes to the children with disabilities, implying that they do not have to perform because they are unable to do so. Different and low expectations may verify to them that they are 'other', they know less and are worth less in the educators' eyes than the other children. One of the participants had a teacher who openly refused to give support in learning.

> *'I don't think that everyone [brief silence] had great expectations of me. Because now, if I meet a teacher who taught me 20 years ago… and I talk with them and say what I am doing, what I have done in my life, they almost get shocked, because it doesn't meet their expectations.'*

> *'[…] And I had tried to study but they said: "No, we can't help you."'*

> *'But four or five years later I was in a private school, and they really helped me.'*

The participants' *general experience* was that when meeting new people, they sense negative stereotypes at the very first encounter which reduce or even disappear over time by their becoming better acquainted with each other. However, there was an

example that mentioned an assistant who was dismissed because she was not able to discard her negative stereotypes. The most common stereotypes in relation to people with disabilities are as follows: they are dependent, vulnerable, amoral, less valued regarding morality, superhuman heroes, asexual, pathetic (Wendell, 2010).

> *'I had one assistant,... she was earlier sometime, and she didn't fully understand that I was not fully disabled. I talked her when I employed her, I told her: "Yes, I am studying." She told: "yes, OK". And then she started a job, and she came home to me, and my book was lying on the table she was surprised: "OOOOh, you are reading!"'*

> *'When you go to the shop, strangers, yeah, that is… some kind of… they see you as, as an alien, a bit. So, they feel, you think, I am… you are different from me.'*

Another difficulty that emerged *in every interview* was that people ignore them, treat them as non-existent and turn to the accompanying person instead. I also had the same experience during the observations, although it is very important to underline that it is easily reversible. Every time the participants' parents or personal assistants explained to the receptionist, shop assistant, waiter etc. that her/his client was the person in the wheelchair, they immediately approached the person concerned in a respectful manner. This implies that *stereotypes are so strong that they prevent the initiation of interaction* despite the presence of a positive and acceptable attitude.

> *'Yeah, as I said, it depends… in my, in my own community, it's no problem. I can see… they don't have a bad attitude… towards me but when you go to bigger places, for example Oslo, it is more usual to look down on people with wheelchairs… and as I said, when you are for example at a doctor and you are with your assistant, or your parents, it's usual that they are… talking not to you but they are talking to my parents or my assistant. "Hello, I am here!"'*

> *'[…] yes, you saw, the repairman was here, he was not talking to me, because he doesn't understand that I live here, and I know what the problem is. He doesn't think that. I experience this all the time, when I am in the shop, and sit in my wheelchair, they talked to my assistants.'*

People with visible disabilities must deal with the inquisitiveness of others, as their difference in appearance arouses curiosity concerning their physical abilities. It may manifest itself in staring, but even in asking too intimate questions about satisfying their needs or sexual life (Reeve, 2012). It again emphasises the 'otherness' of people with disabilities because we do not normally ask anything about other people's urinating habits or whether they have a sexual life. People who behave this way show less respect towards people with disability, do not adhere to the unwritten rules of politeness and convey the notion that people with disabilities are to be treated differently from able-bodied persons.

> *'[…] yeah, but one more thing… People and society ask me all the time: "Can you have a partner, can you have a sex-life?", can you... yeah. And this is irritating. Because of course, I can have a sex life, I have a normal sex life.'*

A conveyor of psycho-emotional disablism is not necessarily an unknown person, it may be an otherwise supportive family member (Reeve, 2004).

'When I wanted to go to Germany, they were not so positive, they were thinking: 'No, this is too hard, you can't make it on your own and you can't organise your life, and so on. They were really worried. And that time, […] I was at home, I hadn't lived on my own anywhere else. Especially for my mother, it was really hard thing. She was really, really sceptical. Before I left. And then I left, I feel she was so sceptical if I could do it or not. I myself was starting to get negative. And I said: "Maybe I shouldn't go, maybe I can't handle this life." '

'My mama and the doctor said: "You have limits, it's not good for you to walk a lot, so it's good for you to have a wheelchair, to sit in it sometimes." And I denied it: "It's not happening." But my mom talked, and talked, uhm… this, this summer I've got a wheelchair. In my apartment now, but I don't use it. But it is here [laughing].'

The role of local governments was repeatedly mentioned in the interviews in relation to claim procedures and the attitudes of civil servants. In these cases, indirect and direct disablism combine: the personnel's negative stereotypes and prejudices (in a direct form) influence decision-making with regard to claims and assistance, and if they come to the conclusion that there is no justified need for assistance or an accessible apartment, structural obstacles (in an indirect form) remain.

'[…] when I was applying to the assistant, at first the answer was that you had to vegetate to get an assistant. You had to be extremely ill to get an assistant. And that is not correct… so I don't talk with them, just I know what I want. Yeah. So… it's problematic with the local government, because they want to tell us how we should be, where we should be… yeah. They told me for instance that I should not use an assistant when I am travelling.'

'I applied to get support, they told me that I could stay inside, in the apartment. So, they thought that people with disabilities should not do what people without disabilities do.'

3.3. The impact of psycho-emotional disablism on the participants

People with disabilities deal with psycho-emotional disablism in various ways: some negotiate it in a very constructive way, whereas others cannot do so for various reasons. Consequently, their reactions have numerous aspects: from fiery resistance to a demonstration of outstanding ability or from performance to passive resignation. Furthermore, it differentiates the ways that their self-concept is formed. There is a significant difference between those who say, 'I am disabled because I am not able-bodied' and those saying, 'I am disabled and proud' (Reeve 2014, 2012, 2002).

Reeve highlights *internalised oppression* as the most destructive effect of psycho-emotional disablism on psycho-emotional wellbeing and as such it has a negative influence on self-concept and self-esteem (Reeve, 2002, 2004, 2012, 2014). She also underlines that internalised oppression is not a common and general experience, and that it can be prevented by resistance and protection.

'I think it's normal for people with disabilities that they can't hang out with all the other children.'

'And they said, "Come to fix it." And they didn't, and I should fight for it, eventually, and it was my fault that I had no social life, I am too vulnerable.'

'uhm, I really wanted to study here, but I am terrified, I am not going to… uhm, uhm, to do that, because I knew, I would fail. I wouldn't make it in normal terms.'

'– Now I'm feeling extremely lonely.
– You had no friends?
– No, I don't have any… I am, I am ashamed of my disability.'

Although internalised oppression was experienced by the participants, resistant rejection was a more usual reaction to disablism.

The majority of the participants reported that a 'twist' happened to them when they were able to reverse negative attitudes and stereotypes expressed towards them as well as low expectations about their potentials, and, hence they were capable of proving what they could become and resisting internalisation of negative attitudes and stereotypes.

'[…] And, and then I left, I feel she was so sceptical if I could do it or not. I myself was starting to get negative. And I said, "Maybe I shouldn't go, maybe I can't handle this life." […] I could manage independently as well. So therefore, when I got back, I decided to move into an apartment. It was not as difficult as before, because they were convinced that I could manage myself. So it was much easier. Because I… I really show them I'm able to manage myself. So that was uhm… uhm… really important period in my life. Actually, because… because it's changed, everything was changed. They are convinced now, I have really proved to them that I can live my life myself. So, everything was easier afterwards.'

An attempt to conceal their disabilities also appeared among the participants. However, this may only be a reaction of those who do not have any major visible impairments (Reeve 2012; Wendell 2010; Goffmann, 1963). Concealing or making a disability invisible also implies that the person with the disability accepts negative social perceptions and tries to conceal their impairment in order to prevent a consequent loss of social value.

'When I meet new people, yes I can mention that… so I stopped using that word [CP]. Then I meet people I say: "Really strange arm, it's very funny. Don't worry, it doesn't bite." [Laughing] And I don't mention that I have a diagnosis.'

'Yeah, I had a friend… I had a friend with a problematic arm, and he has not accepted it. But… he is hiding the arm in his jacket, trying to hide it. But you have to accept your disability! But, yeah. He said that people cheat him he is stupid.'

When choosing a partner and in intimate relationships many felt that their physical impairment reduced their chances. This was *the only time* during both the interviews and the observation when physical disability was labelled as a major obstacle, even if for different reasons, regardless whether the disability was visible or imperceptible.

Firstly, ableism presents us with an ideal image of what our body is supposed to be like, which is in fact only realistic for a small minority of people, and it severely undermines the self-concept and self-esteem of everyone (Wendell, 2010). Accordingly, it is not at all surprising that it seems very unlikely for someone to be attracted to people whose bodies have been subject to observation but only on account of their dissimilarity, or have been objectified and examined by medical doctors only to identify and, if possible, heal the defect.

Secondly, due to their physical state they usually need help when taking care of a baby, but instead of personal assistance, they would prefer to have a partner with whom they can share the child-raising tasks.

Thirdly, as they need personal assistance to lead an independent life, when starting a life with someone the number of persons living together in cohabitation would amount to at least three.

In this respect, negative stereotypes re-emerge, namely being treated as dependent and vulnerable.

> *'And we mentioned a boyfriend (light laughter) […] Of course,… I don't know if someone can accept who I am, I have needs and would like help. And so I don't know if there is someone who can accept it.'*

> *'– What do you think, your bigger barrier, your bigger difficulty in your life is? Your disability or maybe your extreme tiredness? Or something else?*
> *– As a boyfriend, I would say my physical part.'*

> *'I think it's difficult to find a man who really wants to make a family with me. I don't know if he exists. My ex-boyfriend, he was such a man, I think, but it's too difficult.'*

> *'But I don't know if I want to live with someone else and of course I want to, but... because at the beginning my ex wanted to live together, I was like…I didn't want to live with him, because there is the staff, my assistants…'*

> *'It's really difficult to have a relationship. I think, people are afraid of people in wheelchairs. They assume I am helpless, and I need help with everything.'*

Reeve stresses the dangerous impact of psycho-emotional disablism on identity. All the participants defined themselves as people with a disability but not as disabled people. They underlined the importance of this distinction because they object to and reject the stereotype that leads people to assume that their disability affects all areas of their lives, and to fail to take into consideration who they are, what they are capable of and who they could become.

> *'I cannot let my disability problems define me, if I let them define me, I will have more problems.'*

Reeve regards disability activism or joining any disability organisations as a form of resistance, as a positive reaction (Reeve, 2002). None of the participants had joined such organisations, and there was even an opinion that considered the 'jointly, together' approach an alternative to other forms of segregation and, thus, opposed it.

> '[…] it's some commune, I don't like that, good, I have a disability, but I don't need it… I think I would like a normal place.'

Pride also emerged as a form of resistance against internalised oppression, although not in relation to the participants' disabilities but to their achievements.

> 'I was in a bike-competition, 73 km [laughing]… It was horrible weather. It was rainy, 4 degrees, and very windy. The strong wind was against me all the way [laughing]. So, it was lovely weather [laughing].'

> 'And when I came back I was smiling and… I managed it myself! But I was also able to show them that I have -a disability- but I achieved it!'

> '– I decided, I know what I want to do, and that's all I work on.
> – A lot. And you don't give up. Never. [Laughing]
> – Mhm… [Satisfied nodding]'

> 'So, it was a really important thing to do. Not for only myself but for them (the parents), as well. But also, for other people with physical disabilities. You should know you have many opportunities and possibilities. If you notice them, and if you organise everything and do your best, you can achieve.'

All the participants except one have enough self-confidence to make future-plans and regard their prospects of the future with more or less confidence and anticipation. One, though, severe lacks self-confidence, is hardly able to fight for her/himself and is very uncertain about her/his future.

> '[…] and I've been actually, like I've said, several times, I don't live my life, I just exist.'

> 'I am really, really looking forward to my future, of course. And I am excited to see what kind of experiences and opportunities I may have. Of course, I'd like to… to… my home and my life. And this way.'

SUMMARY

This study analysed the experiences of persons with disabilities in compliance with Reeve's concept of psycho-emotional disablism. As the analysis demonstrated, each participant has encountered direct or indirect disablism, or rather both. All highlighted the existence of *negative stereotypes*, suffering from them on a regular basis when interacting with others, and they mentioned the significant impact the stereotypes had on their wellbeing and social participation. These elements correspond to Tøssebro's analysis (2016), according to which Norwegian welfare measures aiming at ensuring an equal quality of life for people with disabilities did not meet all the expectations and hopes held. Although family ties became stronger in their lives, employment rates, the social net, inclusion and participation have not changed significantly.

Despite the fact that negative stereotypes occur in every segment of society and have a ruinous effect on the everyday life and health of people with disabilities, these issues are often ignored in discussions on disability.

If a person with a disability cannot cope with stereotypes, they may withdraw from social participation. Internalising a stereotype extinguishes the fight against it, and makes the people degrade themselves to being less valued members of society by regarding their disability as the reason for social exclusion, in spite of prevailing social attitudes (Reeve, 2012). Feelings of being 'other' and incapable, i.e. that they cannot influence it and rather let it control their lives, will intensify. All the participants with only one exception resist this internalised oppression and, based on their stories, they consider negative stereotypes as an everyday inconvenience that affects their wellbeing and social participation. They keep fighting against them by various means, rather than surrender.

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As Seamus Hegarty elaborated: 'In an ideal world there would be no special schools since every child would receive an appropriate education in a local community school. No country is near achieving that goal, apart perhaps from Italy, and it has to be assumed that special schools will feature on the map of special education for some time to come. But that does not mean they can continue unchanged. Special schools have many advantages – concentration of expertise in teaching pupils with various disabilities, modified curricula and programmes of work, adapted buildings and equipment, training opportunities for staff, and links with local employers and post-school training agencies. These are the very things whose absence from ordinary schools makes them ineffectual in educating pupils with disabilities. The challenge to special schools then is to find ways of sharing their expertise and resources, and of embedding them in a wider educational context. Some special schools have already begun to develop outreach programmes. This can entail setting up working links with neighbourhood ordinary schools where staff and pupils are shared.'

'Some special schools act as resource centres, providing information and consultancy to local schools, organizing support services for families and contributing to in-service training activities. Discharging these functions successfully requires considerable changes within special school staff. New skills must be developed and new attitudes fostered. Transmitting a skill to others is not the same as exercising it oneself, and operating across several schools or in the community is very different from working in the closed confines of a single special school.'

'The most important changes required are attitudinal: staff who are jealous of their autonomy and intent on maintaining lines of professional demarcation will not set up effective collaboration. There must be a willingness to move beyond existing institutional bases and any status that may go with them, and to work co-operatively in whatever new structures may be advised. The upshot of all this is that special schools of the future could be very different from now. Emphasis would move away from educating limited numbers of pupils in relative isolation towards acting as resource centres. The latter could encompass curriculum development, in-service training, the collection and evaluation of equipment and computer software, and specialist assessment, as well as advice and consultation on all matters relating to the education of pupils with disabilities. These resource-centre functions are important in improving the standard of special educational provision regardless of where it is provided. By capitalizing on available experience and establishing a bank of information, materials and expertise, this offers a powerful model for making best use of frequently limited resources. If special schools have to make changes, ordinary schools have to undergo revolution. Ordinary schools have generally failed pupils with disabilities and major school reform is necessary before they can make adequate provision for them.'

'This reform must operate at two levels: the academic organization and curriculum provision of the school and the professional development of staff. The former requires rethinking the ways in which pupils are grouped for teaching purposes, the arrangements that schools can make for supplementary teaching and the modifications to the mainstream curriculum that teachers can make so as to give pupils with disabilities access to it. All of this forces major changes in teacher behaviour. Attitudes, knowledge and skills must all be developed to create and sustain a new kind of school where those previously disenfranchised are given an equal say and narrow concepts of normality are discarded.' (Hegarty, 1994, 16). Hegarty continues: 'Preparing pupils with disabilities for adult life is a particular challenge for ordinary schools that run integration programmes. Many special schools have devoted great efforts to this area and have well-established leavers' courses. They also benefit from the greater control they can exercise over pupils' environments and exposure to the outside world. Ordinary school staff have to find ways of ensuring that pupils do not miss out on the systematic preparation they would receive in a good special school, and they must often do so with fewer resources and in contexts that allow for less control.' (Hegarty, 1994, 45)

The debate persists and has gained new impetus fuelled by the controversial findings of follow-up research conducted on current experience of integration in schools. A UNICEF Innocenti Insight study of 2005 highlights the situation in CEE/CIS countries and the Baltic States: 'The education debate is still very active. There are arguments that integration of children with disabilities into mainstream classrooms can be a drawback for some students, both disabled and non-disabled persons. That may be a question of adequate resources – a persistent and important issue. There is a case in the CEE/CIS region for linking special education schools with local mainstream schools to help to break down the tradition of segregation.

'In some Western countries, there is a trend to co-locate special schools on the same site as mainstream schools in the belief it provides the 'best of both worlds'. Serious efforts towards integration are being made in some countries, notably Bulgaria, Hungary, Romania and Macedonia.

'Where integration has occurred, it is largely accomplished by being at the same location as and/or mixing with mainstream students, rather than integrated or inclusive classrooms. Curricular integration, where children with disabilities learn together in the same classrooms with the general student population, is still seldom seen in the region – and where it is, it is often unplanned and, therefore, unsupported. In Albania in 1996, as the Country Report notes, for the first time 'the integration of pupils with disability in regular school' became a declared policy goal – although the details of how to do this were not specified. A recent survey by the Albanian Disability Rights Foundation found that the integration of children with disabilities was quite limited and done largely in response to pressure from parents of children with moderate disabilities. In Hungary, where the special school system was retained, enrolment of children with

disabilities in mainstream schools started spontaneously in the mid-1990s. However, schools 'did not have the technical, pedagogical and conceptual conditions necessary for the integrated education' of children with disabilities.

'The resistance of attitudes against the integration of children with disabilities in mainstream schools cannot be underestimated. In echoes of the 'charity' treatment of children with disabilities, parents and others may support integration only conditionally, e.g., the proviso that including children with disabilities in a regular classroom does not detract resources from non-disabled students. Additionally, there is substantial passive resistance incumbent in existing education systems and other social services.' (UNICEF, 2005, 20).

In the literature we can find several examples: 'Although parents were happy with the progress of their child at the school, they were disappointed about social outcomes. This was in part due to the fact that many children with disabilities came by bus from out of catchment; they had to make a new friendship base, and there was no opportunity for carrying it on out of school hours.' (Avramidis, Bayliss & Burden, 2002, 150)

The UNICEF study continues with a quote from the Lithuania Country Report of 2002: 'Policy, law and practice have been linked in Lithuania to make strong progress in special needs education. The 1991 Law on Education recognized the right of children with special needs to be educated in schools closest to home. School committees started using more restrictive criteria for accepting children into special schools – a crucial gatekeeping function. Amendments in 1998 gave broad definitions of the role of pedagogical-psychological services in assessing special education needs and gave parents and children the right to choose the form and place of education. The law stresses integrated education and the right of persons, even those with complex or severe disabilities, to be educated.' The UNICEF study then refers to staffing issues: 'The lack of teachers who are adequately trained to work with children with learning