## EÖTVÖS LORÁND UNIVERSITY FACULTY OF EDUCATION AND PSYCHOLOGY

## **THESIS of DOCTORAL (PhD) DISSERTATION**

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# Identification of factors supporting inclusion based on the experiences and opinions of Norwegian and Hungarian adults with cerebral palsy

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#### **1. POSITIONING THE TOPIC**

The topic of the thesis is an approach a much-studied topic from a different aspect. The co-education, inclusive school, social participation, social inclusion of persons with disabilities has been a central topic of research for decades, even if the used terms and focus have changed. However, this studies primarily approach the issue from the perspective of the school, the community, society, and the environment, and the voices and opinions of persons with disabilities are rarely articulated in them.

We have little knowledge of the lives of people with disabilities who study, work, live an independent life, find a partner, raise a child, that is, live their lives like everyone else. *The novelty of the research's point of view is that it focuses on those people who participate in social processes despite existing barriers.* I felt necessary to summarise the experiences in order to refine and clarify the image formed about them, to expand knowledge and to contribute to the complex interpretation of disability.

Another novelty of the approach to the research topic – and I hope, contributes to the credibility of the results obtained – is that I involved young adults with disabilities from two countries, Norway and Hungary. I compared the opinions and experiences of the participants of the two nationalities, revealing the differences and specifically looking for common points.

Disability activists, disability studies (DS) and critical disability studies emphasize the principle "Nothing about us without us" in politics, ideology and in all social processes (Charlton, 2000). The principle also appeared in research/scientific trends, the value of everyday knowledge and experience was strengthened, drawing attention to the contradiction that scientific discourses often discuss people without presence of people concerned, so their opinions do not appear (Zarb, 1992; Borg, Karlsson, Kim, & Mccormack, 2012). The primary goal of the dissertation is to give voice to the opinions and experiences of people with disabilities, to include their opinions in the scientific discourses. The thesis interprets co-education, social coexistence and participation from the perspective of a person with disability, and analyses the impact of experiences on the life of a person with disability.

Hungary signed and ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2007, and Norway signed it in 2007 and ratified it in 2013. Both countries committed themselves to revise their legislation based on the principles of the CRPD.

The CRPD fits into the series of UN human rights documents, and as such, it does not list new rights, but it reaffirms that all persons with disabilities must enjoy all human right and fundamental freedoms (Halmos 2019). The ratification of the CRPD theoretically opened up and legally ensured for people with disabilities access and participation in both countries. The realization of principles and goals of the CRPD in legislation has a significant literature (Gradwohl & Vámosi 2012; Hadi, 2013; Brehmer-Rinderer, Zigrovic, Naue, & Weber 2013; Lawson 2014; Brennan, Rice, Traustadóttir, & Anderberg, 2016; Brennan, Trausdottir, Rice, & Anderberg, 2018; Mikola, 2017; Halmos 2019; Gulya & Hoffman 2019; Boros 2019; Grue, 2019; Sándor & Kunt 2020; Kiss, Primecz, & Toarniczky, 2020; Chhabra, 2021). Petri (2019) criticizes the human rights studies for basing its results primarily on document analysis and following legal changes, and not on empirical examination of the effects on people's lives. He asked whether the human rights approach is effective in "addressing systematic exclusion" (Petri, 2019, p.31.). Although the doctoral research does not attempt to answer this question, but our results may bring us closer to the answer. Grue (2019) comes to the conclusion in the connection with the criticism of the CRPD that full participation in society and true equality is utopian. Grue writes about "inclusive marginalisation", that means "a) rights are formally or legally guaranteed but not politically enforced, resulting in b) inclusion without genuine equality of opportunity" (Grue, 2019, p.11.).

The research is at intersection of several theories and sciences (general and special needs education, law, general and social psychology, sociology, DS), the focus of examination and the placing of the results in a broader context required a multi- and transdisciplinary approach. Its position based on DS, the focus of the study is not on the disability, but on the people with disability. The DS are interested in how the people with disabilities live, under what conditions, with whom, and they never see the people with disabilities as an object, but as an acting subject (Borg, Karlsson, Kim, & Mccormack, 2012; Könczei, Hernádi, Kunt, & Sándor, 2015).

The focus of DS is mapping the social, cultural and political causes of disadvantage and exclusion. The studies with other approaches also tend to emphasise the negative aspects and the existing barriers. For a complex understanding of disability, it is necessary to look at life situation of people with disabilities from a broader context, the examination of the social and built environment, existing obstacles, disadvantages, exclusion and oppression is unavoidable. However, the purpose of the present study goes beyond these topics and

it is interested in the voice and experience of those people who, despite all existing barriers, limitations and oppression, participate in social life.

The dissertation is structured around three prominent and interrelated goals (1. figure). In terms of its content and focus of examination, the primary goal is to *identify factors supporting social inclusion and participation* based on the personal experiences of the participants in the study. As a second goal – and here the listing and numbering does not mean order –, I considered to give voice of people concerned, the dissertation aims to *bring the experiences and expressed opinions* in relation to inclusive school and social inclusion *of children and adults with disabilities into the scientific discourse*. The study particularly focused on the *comparative analysis* of the opinions and experiences of *Norwegian and Hungarian* participants, identifying the different and the same factors. Personal experiences, the opinions expressed and the emotions accompanied often contain critical elements that go against the prevailing social and political discourse, broadening and shading our knowledge, and contributing to the *complex interpretation of disability*, which can be considered the third important goal of the study.



1. Figure Connection of goals in the study

## 2. METHODOLOGY OF THE RESEARCH

## 2.1. Participative paradigm

The methodological questions of the research and the tools used for data collection and analysis were decided and selected on the basis of the researcher's ontology and epistemology. I used qualitative methodology to map experiential knowledge and related opinions and naive theories, to explore the factors supporting inclusion, and to build a possible theory.

Based on the interpretation of disability of DS, and the principle "Nothing about us without us", a significant part of DS' studies fits into the participation paradigm, as does this study. Participative research is not a uniform realisation of the characteristics of the paradigm, desirable to the same extent in all research, but rather a researcher's approach that influences the decisions related to the research. The realisation of the characteristics varies from research to research, the researchers adapt them to their own methods, opportunities and limitations. The central feature is the changing of the researcher-researched relationship and the empowerment (Király, 2017). The expectations related to the dissertation, as well as the restrictions introduced during the examination due to COVID19, influenced this research, so the characteristics of the participative paradigm were realised to a different degree, which is summarised in Table1.

Characteristics of participative	Realising the character in own research	
research		
Researcher attitude: the involved people are capable persons with valuable knowledge who can be involved in research-related decisions and activities.	Done. The idea of the research was also given by this researcher's attitude, which determined the creation of the research framework, the conduct of the research and the presentation of the results.	
Involvement of people	Partially done. The participants were the people concerned,	
concerned.	but their participation in the creating of the research	
	framework and the analysis of the results was limited.	
Inclusion of everyday	Done. The research is based on the examination of everyday	
knowledge	experiences and the opinions expressed in this regard.	
Central focus is empowerment	Done. This principle was in the focus in all along research.	
_	The participants were involved in the decisions related to	
	interview's topics, in controlling the interviews, and in the	
	first step of analysis. I endeavoured to create a more	
	partnership relationship, which was based on trust and	
	mutual respect: introduction-informational conversation	
	before the examination, consciously braking the traditional	

	research roles, the subordinate-superiority relations emphasising the co-construction of knowledge			
Raising awareness and training	Partially done. The training of the participants not was goal.			
of participants.	Based on the participants' feedback, their awareness and the			
	representation of their interests was strengthened.			
Political activity	Not done.			
1 table				

1. table

The characteristics of participative research by Király (2017), and realising of the characteristics in the own research

### 2.2. Constructive Grounded Theory

Grounded theory (GT) is a research methodology developed by Glasser and Strauss (1967), which aims to build theory from data (Corbin & Strauss, 2008). Charmaz, Thornberg és Keane (2018) disputes the GT method's early position that the respondents' opinions can be examined on their own and a new theory can be build up from them by following the described steps. According to their opinion, the researcher's approach and starting point, the study situation, and the participants' reporting together influence the result of the study. The resulting analysis or theory does not only mean the mapping of the knowledge and theories of the respondents, but a co-construction of the researcher and the respondents. They called their method constructive grounded theory, and I used the methodology they suggested in our study. The constructivist approach emphasises the existence of subjectivity, the , viewer is part of what is seen (Charmaz et al., 2018 p.730). The starting point is defined by the researcher's social class, gender, ethnicity, studies, and other sociodemographic characteristics, which must be clarified at the beginning of the research. It does not demand a value-free, value-neutral point of view, but a reflexive approach to the values represented. Reflexivity is especially valued in this approach, the researcher must find the elements of the aforementioned starting position in the resulting knowledge and reflect on their influence.

The steps of the constructive GT analysis follow the steps of the original GT analysis. Data collection, coding and analysis is a circular process that takes place in parallel with each other. The first step is to select the topic and the sample of the first data collection, and then the data collection begins immediately. The data collection and the analysis, along with the exploration of the literature, take place in parallel and circularly in the GT method. As the analysis progresses, the research questions can change, become more precise, are supplemented, new questions generated, and the sampling may also change (2. Figure).



2. Figure

Correlation of data collection and analysis based on the GT method in my own research

#### 2.3. Research process

20 participants (age 22-42; 6 Norwegian, 14 Hungarian) with different, often complex support needs were involved in the research. One person has a primary education, eight of them completed secondary, eleven of them higher education. Four persons have no job, one participant is a university student, one of them raises a child currently, seven people work part-time and seven in full-time. Characteristic features and support needs of the participants diverge from each other at a great extent. In terms of their moving abilities, it ranges from invisible to severe disabilities. Eight participants walk indoors and outdoors independently, but their balance or coordination are limited, and it may happen that they need personal assistant or using equipment in difficult conditions or to cover longer distances. Seven participants walk indoor by using some kind of equipment (sticks, walker, etc.), but, in difficult circumstances and to cover longer distances they need personal assistant and wheelchair also. Five participants have severe physical difficulties, they need wheelchair and personal assistant in any circumstances. 19 participants reported any other difficulties, which affect their social position. The other difficulties may mean medical/pedagogical diagnoses (for example: visual disability, intellectual disability, arthritis, panic-attack, depression, epilepsy, tumour, dyslexia, dysgraphia etc.) and obstacles mentioned by the participants (for example: vision-, language-, memory-, or attention difficulty, orientation problem, spine problem etc.).

I used *episodic life story interview* and *timeline interview* to collect the data. Life story interviews examine the subjective meaning of the respondents' stories. The episodic life story interview means, that interviewer limits the topic of the story and asks the respondents to tell his/her life story along the theme (in our case, social inclusion, participation) (Plummer, 2013). The timeline is a *visual representation* of the storyteller's own life path. The storyteller can mark the most important events on the timeline, and she/he can indicate that the marked events *positively or negatively influenced her/his social participation, social position* according to her/his opinion. The participants could see the told stories in a different position, she/he had the opportunity to supplement what was said, and the connections could also emerge for her/him based on other aspects. The participant was involved in the first step of analysis by the visualizing the life path, thus the role of the participant and researcher was restructured, the participant was empowered, and a more equal relationship was created, breaking the traditional wall between the questioner and respondent (Adriansen, 2012).

Two Hungarian participants are married with each other, they insisted the joint interview, so a total of 19 interviews were recorded and transcribed verbatim. The length of the shortest interview is 45 minutes, the longest is 2 hours and 6 minutes.

The steps of the analysis are long and interconnected processes. Corbin & Strauss (2008) recommended sequence, but with the increase of data, the steps must be carried out again and again, the already existing data and results related to the new data must be reviewed, in order that the new correlations should become recognisable. The steps of GT content analysis are summarized as follows (Corbin & Strauss, 2008):

- 1. reading the transcribed interviews
- 2. conceptual analysis: open coding, focused coding: with the exploration of relationships between codes until the creation of categories and main category
- 3. contextual analysis
  - 3.1 exploration of context: 1) macro-level conditions, 2) micro-level: emergence of macro-level conditions in everyday life of the participants
  - 3.2 identification of processes
- 4. integration of categories: identification of factors supporting inclusion
- 5. theory-building: summary presentation of the obtained results

Figure 3 summarizes the entire process of examination and analysis in our research.



#### 3. Figure

The order of the analysis steps in the research

## 3. RESULTS

The results are first presented in summary along the goals, and then the most important results are presented for each goal. Table 2 summarizes how the analysis steps supported the realization of the goals, assigning the research focuses used in the given step, and also the obtained result.

Goals	Analysis steps (according the GT)	Research question and research focus	Result
1. Exploring subjective experiences and opinions related to inclusion	open coding $\rightarrow$ focused coding $\rightarrow$ categories $\rightarrow$ main category	What concepts and categories can be identified in the life stories?	System of categories, main category: participation (4. Figure)
	The first step of contextual analysis: exploration of macro level conditions	What kind of legal, social and physical environment do the two countries provide in relation to the categories? Are there significance differences in the provision of legal, social and physical frameworks?	Ensuring access in the two countries: realization of the relevant articles of the CRPD
2.a Comparative analysis of Norwegian and Hungarian participants' experiences and opinions	The second step of contextual analysis (micro level): emergence of macro- level conditions in everyday life of the participants	How do the legal, social and physical environment appear in everyday life of the participants? Do the differences in everyday life the different legal, social and physical environment?	The experiences of the principle of accessibility and participation on equal basis with others in everyday life 1. physical environment: physical accessibility equipment, personal assistance 1. social environment: stereotypes, behaviour, discrimination
	The third step of contextual analysis: identification of processes	What supporting factors and barriers are mentioned in relation to education, independent living, social inclusion? Are there common experiences? Are there any differences between the Norwegian and Hungarian participants?	Identified processes: 1. education 2. everyday life situation 3. partnership, family 4. work

2.b Bring the experiences and expressed opinions in relation to inclusive school and social inclusion of children and adults with disabilities into the scientific discourse	Involvement of other sources: literature review	Comparison of the expressed experiences and opinions with the theories and research results found in the literature.	Identification of the same and the different experiences and opinions → identified novelty
3. Identification of factors supporting inclusion	Theory-building: integration of categories	Can the factors supporting inclusion be identified in the various processes? Can a theory, independent of nationality, be built based on the collected data?	

2.. Table

The analysis steps supported the realization of the goals, assigning the research focuses used in the given step, and also the obtained result.

## 3.1. Exploring subjective experiences and opinions related to inclusion

The result of the first goal is the system of the categories and the main category (figure 4). The categories provided the basis for the comparison of Norwegian and Hungarian participants' experiences and opinions, and for the theory building.



#### 4. Figure System of categories

Participation was identified as the main category, and four categories affect participation: 1) difficulties in abilities, 2) supports, 3) interpersonal relations and 4) self-concepts.

- Difficulties in abilities. We included in this category all the mentioned factors and events that are related to the abilities, condition, or disability of the participants. This category contains three subcategories: learning difficulties (typically difficulties in reading, writing, or counting), physical disability and other difficulties, such as sensory impairment, depression, panic attack, orientation-, attention, memory problem, difficulties in communication or in speech etc.
- Supports. We evaluated the types of assistance mentioned by participants. Within the category the collected data were organized into four subcategories as follows: personal support, physical support, developments, and the situational adaptation.
- 3) Interpersonal relations. This category proves to be particularly important for participation. Its subcategories are 1) personal relations, such as family ties, peer, and friends etc., 2) attitude (towards participants and general social attitude and

stereotypes in relation to disabilities based on their own observations), and 3) interactions (actions-reactions with the social environment, including the entire process from the input to the emerging feelings during the process).

4) Self-concepts. This category contains terms reflecting to the self and can be grouped into three subcategories: A) autonomy (experiences in relation to power, independence, vulnerability, dependency), B) self-determination (every participant came up with a self-determination which were mostly reflections to their adulthood) and C) sense of disability (in terms of participation, it was generally emphasized that acceptance or non-acceptance of themselves and their limitations is crucial).

# **3.2.** Comparative analysis of Norwegian and Hungarian participants' experiences and opinions and bring them into the scientific discourse

Examined factor		Norway	Hungary	
Macrolevel condition: legal regulation and background of accessibility				
support services		$\checkmark$	limited	
personal assistance	personal assistance		no	
accessibility of community services and facilities for the general population on equal basis with others		✓	limited	
accessibility on equal basis with others in the identified social processes	education	$\checkmark$	limited (based on the recommendation of an expert committee)	
y oi otl ied	everyday life	$\checkmark$	$\checkmark$	
accessibility basis with the identif processes	partnership, family	$\checkmark$	✓	
acc bas the pro	work	$\checkmark$	$\checkmark$	
<i>micro level condition:</i> emergence of macro-level conditions in everyday life of the participant and participation in the identified social processes <b>EDUCATION</b>				
accessibility of building		$\checkmark$	limited	
mobility aids and devices		$\checkmark$	$\checkmark$	
devices and assistive technologies for education		✓	no	
personal assistance		$\checkmark$	no	
social environment		typically negative experiences	typically negative experiences	

Table 3 summarizes the results of the contextual analysis.

situational adaptation	both positive and	both positive and negative			
	negative experiences	experiences			
full participation on equal basis	both positive and	both positive and negative			
with others	negative experiences	experiences			
<b>EVERYDAY LIFE SITUATION</b>					
accessibility of buildings	generally $\checkmark$ , sometimes	limited			
	no				
accessible apartment	$\checkmark$	very limited			
accessibility of transport	$\checkmark$	limited			
mobility aids and devices	$\checkmark$	limited			
personal assistance	$\checkmark$	no			
social environment	typically negative	typically negative			
	experiences	experiences			
full participation on equal basis	limited	limited			
with others					
PARTNERSHIP, FAMILY					
personal assistance	$\checkmark$	no			
social environment	both positive and	both positive and negative			
	negative experiences	experiences			
full participation on equal basis	$\checkmark$	$\checkmark$			
with others					
WORK	WORK				
accessibility of physical	$\checkmark$	limited			
environment					
personal assistance	$\checkmark$	no			
social environment	both positive and	both positive and negative			
	negative experiences	experiences			
full participation on equal basis	$\checkmark$	$\checkmark$			
with others					

3. Table Summary of contextual analysis

There is a significant difference between the two country in examination of macro level condition. Rights ensuring equal opportunities for people with disabilities in Norway comply with the CRPD (Chhabra, 2021). In Hungary, the right to equal opportunities is ensured, however, the regulations only partially comply with the CRPD, so the provision of the right is only formal (Halmos, 2019).

However, this significant difference decreases in the micro-level examination, and even disappears in the case of experiences related to the social environment and participation in the identified processes. Due to the regulations, the Norwegian participants are generally provided physical accessibility, while in the case of the Hungarian participants these conditions are provided only *limited* or they are *absent*. However, participants reported similar, typically negative experiences and social obstacles when examining the social environment in both countries, which could be divided into 3 groups: 1) stereotypes 2) rude, disrespectful, hurtful or dismissive behaviour and 3) discrimination. There is a

difference in the reports of the participants of the two nationalities: the Norwegian participants mentioned only hidden discrimination, while the Hungarian participants also disclosed discrimination, when they were rejected due to their disability, referring to daily practice or regulatory document. Stereotypes appeared most often in the negative experiences, and the participants often perceive the presence of stereotypes behind insensitive, disrespectful, hurtful or rejecting behaviour and discrimination. Stereotypes have their effect even with a positive attitude, make it difficult or prevent contact with strangers, and can also cause difficulties in positive, secure relationship.

# The participation physically realized in all identified processes, but the full participation on equal basis with others is limited.

Attendance at school is guaranteed for the Norwegian participants, while in Hungary, not all schools accept children with physical disability, so they may even be physically excluded from the education. I only examined those stories when they physically present in the inclusive institution. Positive and negative experiences were mentioned in both countries. One of the attention-grabbing results of the study, 15 participants reported long-term isolation and loneliness. The students with one exception were stuck in the situation and their situation only changed with leaving the institution, and not a single participant remembers a successful pedagogical intervention. It highlights the vulnerable situation of all marginalized children (and it does not matter she/he with or without disability), which they are not able to change on their own. Furthermore, it shed on the lights on the fact that the teachers are not able to solve this situation successfully, and the children can be stuck in the marginal situation for years. The thesis did not have the purpose, nor did it have the competence, but in future researches it can provide a starting point for examinations.

A similar picture emerges in everyday life situations. The physical accessibility is almost fully insured for the Norwegian participants, and is limited for the Hungarian participants. but the differences are disappeared in the examining the social environment. Hungarian participants are more often, and Norwegian participants are rarely physically excluded from buildings, services, and events. They feel in many cases that this is an obstacle that can be overcome, or at least something that will hopefully change in the foreseeable future. However, if they are physically present in everyday life, they may face all of the psychosocial obstacles.

When examining the psychosocial obstacles, a significant difference can be perceived compared to the school. While they had to face social obstacles mainly *from* 

acquaintances and on a daily basis at school, in adulthood they perceive them mainly from strangers and – although regularly, but only – have to tolerate it temporarily.

There were the same experiences related to partnership in both countries. They faced social obstacles when forming relationships, but in an established, stable relationship none of them reported any psychosocial obstacles.

The provision of the physical environment and personal assistance related to also work appeared as a difference in the reports of the Norwegian and Hungarian participants, and the positive and negative experiences related to the social environment did not differ here either. However, the negative experiences only appeared when looking for a job, and with one exception, the participants of both nationalities feel that their acceptance and participation in their workplace is complete.

These results show that securing rights and accessibility to the physical environment is not enough to ensure participation, and the transformation of the social environment, the social accessibility is also necessary. Based on their opinion, the physical and social accessibility is the outsider conditions, and it can be same important factor how much personal, emotional, material resources have people with disabilities, and how much they can mobilise these resources.

The timelines provided a visual reference point in the identification of supporting factors, and highlighted the common junctions and turning points by age.

The marks increasing by age in the timelines, and a typical pattern emerges. The most marked events were related to the personal relations category. The peer relationships determine participation in various social process most strongly in adolescence, and participants were less able to detach themselves from the effects of it, their relationships with peers strongly influenced their lives. *In adulthood, the role of social relationships remains strong, but no longer depend on their impact, but rather provide a secure background for participants to mobilise their own resources for participation based on their personal characteristics.* 

The interesting and important result of the study that only one event was marked as an obstructive factor in the difficulties in abilities category. One participant identified his difficulty in learning as a barrier, due to it he was forced to repeat class. He finally overcame difficulties and graduated as a psychologist. The physical (dis)abilities were not considered and named by any participant as a barrier of inclusion. This result is in line with the social model of disability: not biological impairment but rather social barriers prevent participation in social processes (Shakespeare, & Watson, 2001;

Goodley, 2017). However, compared to the age pattern, the participants' opinions only partially agreed with the social model that emphasises only the role of the social environment. The role of the social environment, especially of the peer relationships were significant in adolescence. However, in adulthood, participants also emphasise the role of people with disabilities and consider it important for social participation. Based on their opinion, existing biological and social barriers and opportunities are only two sides of a triangle, and it can be same important factor how much personal, emotional, material resources have people with disabilities, and how much they can mobilise these resources. Emphasising personal characteristics as an important factor is relatively rarely mentioned in research, and this result can therefore be interpreted as a novelty.

#### **3.3.** Theory: identification the factors supporting inclusion

One of the unplanned results of the study is the co-constructed interpretation of disability. It emerged from the conversation with the participants that the division of society into people with and without disability is rejected. The Hungarian participants find the term "disability" particularly offensive. The Norwegian participants use the term and attach less negative connotations, but they also strongly reject the interpretation of disability. The opinions of the Norwegian and Hungarian participants agreed on the common interpretation of "disability" by society: disability means for people "full inability", and as such does not really exist.

The participants therefore see people as persons with different characteristics – in which interpretation the various impairments and disabilities are naturally present – whose *grouping based on some of their prominent characteristics is forced and discriminative*. The human being is complex phenomena, and it cannot be seen and especially judged on the basis of one emphasised characteristic. The impairment or disability is only *one* of many characteristics of people and does not define people. It is the co-responsibility of the environment and person to ensure that the (dis)ability not become inability.

The interpretation of the main category (participation) and identification the factors supporting inclusion were the last steps of analysis. It was necessary to examine the correlation of categories (Figure 4) again, positioning the categories in a broader context and examining them in relation to the conditions in the identified processes (Corbin & Strauss, 2008).

Participation was defined as the central concept. In our co-constructed interpretation, participation means that people have the right to participate; in order to participate, they may need physical, personal or other support, which are available in accordance with their needs. Taking into account and respecting her/his individual needs may make it necessary to adapt the situation. In order to participate, it also mobilizes its own resources. Inclusive participation assumes reciprocity between community members, it does not separate the into people with and without disability. During the participation, people come into contact with other people, as a member of the community, with the same rights as the others, and they act together with them and not separately next to them. Participation also includes the right of people to make independent decisions about her/his life, to define herself/himself as a member of the community, to develop and live as independent life as possible.

Participation was identified as the main category, and four categories affect participation: 1) difficulties in abilities, 2) supports, 3) interpersonal relations and 4) self-concepts. The factors supporting inclusion are identified along the categories.

1) **Difficulties in abilities**. The participants are people with different abilities and support needs. The study confirms the recommendations that appear only sporadically in the literature (Henman & Foster, 2015; Halmos, 2019), that the various support should not be judged along the lines of diagnoses and established %, but rather by knowing and taking into account the real needs of person.

The physical difficulties can be largely overcome by making, building and transforming the accessible environment, by providing appropriate tools, devices and technology and personal assistance according to needs. If we approach from the perspective of the conditions, then the regulation of the provision of access is the primary supporting factor.

2) **Supports.** *Physical support* makes it possible for people with different characteristics to meet in one space, which is the starting point of inclusion. The accessible environment to all people is defined by the EU based on the "design for all" principle, which also includes the accessibility of buildings, services and public transport (Halmos, 2009; Gradwohl & Vámosi, 2012; Kozma, Petri & Bernát, 2020). In addition to physical support, the provision the various devices and technology also proved to be important.

Personal support. Both children and adults (with disabilities) need a network of supportive personal relationships. On the one hand, supportive relationship means the person with a stable, balanced, psychological background, that provides emotional

fulfilment, security, comfort and can be a serious resource; on the other hand, the network of contacts can *provide support for the asserting rights, establishing the necessary conditions of participation, and physical assistance during participation.* 

The presence of support persons can even hinder participation if the support is excessive and solves the task instead of the person. Such can be the presence of a personal assistant, who relives the person excessively or replaces social actors; a parent, if she/he protect the child excessively or does not let him/her leave the child role; the teacher who sets excessively low expectations, etc.

*The supporting persons changes with age*. First the family, later the family, teachers and habilitation specialists is emphasized, around the age of 10 the peers' and around the age of 16-18 voluntary support relationships' supportive role is strengthened. In adulthood, the role of supportive personal relationships weakens, and reliance on one's own resources takes its place.

One of the special groups of personal supports is the *personal assistance* (PA). If the PA system is *adapted to the real needs* of the person, and *suitable and relatively permanent personal assistant* can be employed for the task, it greatly supports the independent live, the participation in society, and the decision-making process of people with a high need for support.

Situational adaptation. Based on the experiences and opinions of the participants, the adaptation of situations is successful if the person managing has *positive attitude*, *assesses and respects the characteristics and needs* of the persons, sets *realistic expectations* and provides *physical and psychological support*. She/he ensures that the *solution of the given tasks adds to the solution of the common task*.

*Developments*. The participants commented very positively on the various developments, they recognize and praise the specialists. They believe that the habilitation sessions were the base of their later progress, supported them on their way, and in adulthood they would need it primarily to maintain their physical condition. No one questioned the necessity of such sessions, but doubts were expressed about the framework. On one hand, the 1x-2x 30-45 minute sessions per week do not achieve their goal, they clearly feel the more intensive, more frequent sessions are successful; on the other hand, their participation was more negatively influenced by sessions that took them out of class.

*Other support*. This category includes the financial support provided by state, such as income, various available discounts. This category was rarely focused on; we did not form an opinion on this category.

**Interpersonal relations.** The category of interpersonal relations is mentioned the most, and is considered the most problematic related to inclusion and participation. The behaviour, attitude, stereotypes shown towards people with disabilities determines the relationship and interactions. It can influence the support received or denied, and the self-image, self-esteem and self-confidence of children and adults (Reeve, 2002, 2014).

The social environment is outstanding important. The psychosocial accessibility identified by Halmos (2009) – i. e., the creation of a positive, accepting social environment – can be matched to factors supporting participation, and its absence can significantly hinder participation in society. The participants consider existing stereotypes to be the main obstacle to psychosocial accessibility. The socially accepted and unconscious tactless, hurtful, neglectful behaviour, rejection, exclusion and discrimination can almost always be traced back to stereotypes and prejudices based on them. Accordingly, the *change of stereotypes* was identified as a factor supporting participation.

The opinions of the participants differed slightly according to nationality on the path leading to the possible change of stereotypes. The Hungarian participants emphasized that the first step in reducing negative stereotypes related to disability is that people with disabilities appear in the social space and their presence becomes everyday. The experience of the Norwegian participants contradicts it, because their presence has been commonplace in the social space since birth, but based on their reports, the stereotypes live in the same way and make their everyday life significantly more difficult (Vissi 2020). The participants of the two nationality agreed on the other possible steps. They consider it very important to provide correct knowledge and to shape social attitudes regarding disability in the widest possible social division. The formation of social attitudes has been broadly interpreted, they involved the disability-image by teachers as well as the disability-image by legislation and regulation or the media. The role of age appeared here as well. Attitude formation could be prevented if the negative stereotypes does not develop. According to their opinion, the people-image conveyed to growing up children would naturally include the people with disability – and/or with other different characteristic –, if they not treated as a separate group, but as people without any discrimination.

**Self-concepts.** The role of personal characteristics as a factor supporting inclusion, participation was also emphasized. The establishment of physical and psychosocial conditions, adaptation of the situation, and a stable, psychological background ensure

access and create the possibility of participation, but personal characteristics also play a significant role in the realization of participation. The following personal characteristics were highlighted as factors supporting participation in the interviews: activity, motivation, the presence of willpower, empathy, the ability to support others, obtaining appropriate training, resourcefulness, decision-making and responsibility, self-confidence, courage, initiative, standing up for yourself, yourself commitment, acceptance of disability, diligence, receptiveness, appropriate and open communication and in many cases stubbornness, defiance. The role of personal characteristics and the mobilization of one's own resources is emphasized by participants, and in my opinion, it is a less-focused and less-examined topic in the literature (Hästbacka, Nygård & Nyqvist 2016).

### 4. OUTLOOK

The grouping theoretical and practical goals is typical if the participative paradigm, but I designated theory constructing as the aim of the dissertation – due to the lack of knowledge. However, summarizing the results, I feel it is necessary to examine which ones increase our theoretical knowledge and which those that can be used in practice. I am doing it, on the one hand, because it follows logically from my starting position – DS and chosen research paradigm --, but I was at least as strongly influenced by the urge expressed by the participants that we cannot stop with expanding knowledge, "let's send a message to the people". Based on our position, the research should indicate some change if it possible.

The identified factors supporting inclusion means knowledge that can be used both for theory and for practice.

#### Theoretical knowledge, contribution to the complex interpretation of disability:

- a) The people-image presented in our theory, where the disability emphasizing was doubted, because by highlighting it – despite our best intentions – we remain in majority-otherness dichotomy and reinforce the separation along different characteristics.
- b) Rethinking the term "disability". According to the participants, many negative connotations are associated with "disability" and it means "inability".
- c) Although, based on our co-constructed opinion, we agree that participation in society is not biologically determined, we qualify the related statement that enabling and ensuring participation is society's responsibility.

On one hand, there was a significant difference based on age during the identification of the factors supporting inclusion and examining the condition of inclusion. *Childhood appeared as a double disadvantage for children with disabilities*. Children stuck in a marginalized, discriminated situation not because of their disability, but because of their age. They experienced exclusion due to their different characteristics, but remained in the situation due to their child status – they could not make decisions about their lives yet. In the case of children, society's responsibility, and even more so the responsibility of those who make decisions on behalf of children – similarly to substitute decision makers of people with intellectual disabilities – is particularly emphasized.

DS deals with the issue of multiple discrimination, but primarily from the point of gender, social class, race and sexuality (Goodley, 2017). However, it pays little attention to the special situation of children and does not distinguish them from adults in its theory.

On the other hand, securing rights and transforming the physical environment is a necessary, but not sufficient condition for ensuring participation: the transformation of the social environment is also necessary. Based on the opinions of the participants, these only provide the external conditions, but the existence of internal conditions is important also. The mobilization of one's own resources, and the personal characteristics of people significantly shape participation.

#### We specifically consider critical comments and knowledge for practice:

- a) The children (with CP) development is not linear, and they need providing education and development appropriate to their educational needs (which includes personal and physical support and adaption of situations and tasks) and sufficient time to develop the child's abilities. In the case of education strictly tied to milestones, failure is most certain both for the child and the teacher, which affects the child's self-image, self-confidence.
- b) It follows from the above that there is wrong teacher's attitude, which tries to decide in advance how far the child can go, and adjusts her/his expectations accordingly. Pedagogical optimism and openness, pedagogical awareness, recognition of one's own stereotypes and the ability to reflect on them are very important, because our results show that *teachers judge lower the limit of the child's abilities than the child is actually capable of.*
- c) The marginalization of children is a general and otherwise well-known problem. *The possible prevention and the inclusion of marginalized children should be given a more prominent role in the teacher training.*
- d) *Stereotypes accompany people with disabilities throughout their lives and make it difficult to achieve and maintain their social status.* It is exacerbated by the fact that they experience it from their family, closer and no closer acquaintances and strangers, which prevent the formation of a realistic self-image and self-confidence, thus affecting their entire life path and quality of life. It significantly determines the school-life, and it prevents becoming independent, finding a job and workplace that matches their qualifications and abilities, and forming relationships. The stereotype also appeared related to professionals who assigned

the different supports, which makes it difficult for the people to receive the rightfully requested support. It would be necessary to *increase knowledge about people with disabilities, to prevent the formation of stereotypes and to take steps to change the existing stereotypes.* 

- e) The support system in Norway is very strong, in Hungary its role did not even appeared in the lives of the participants. In Norway, they are face with the already mentioned problem, that the supports depend on the attitude of the professionals. In Hungary, the available supports do not meet the needs and demands of the participants. In the other words, *in both countries, supports are* not *determined* by real needs, but rather *by political and professional decision-makers*, who determine the system and conditions.
- f) For professionals working with people with CP: the processes that prepare/support social inclusion cannot be limited to development and compensation of physical abilities. People with CP must be considered in their full complexity, both when assessing their status and needs, and when providing support. The mobility limitation is only one of the characteristics of a person that does not determine her/him as a person. Although the international literature often considers CP as a complex disability instead of the former physical disability, on the one hand, this attitude still focuses on deficits/differences instead of needs. On the other hand, based on the review of Pintér & Molnár (2019), although there is a shift away from the emphasis on physical limitations in theory, but the research focuses are still primarily concerned with the assessment and possible overcoming of physical limitations, and the measurement of the effectiveness of interventions aimed at it, which does not indicate a real shift.

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