

Supportive and interfering factors in inclusion in timeline interviews of people with cerebral palsy

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Introduction

Inclusion of people with disabilities is a common topic of studies all over the world, and the opinions and experiences of people with disabilities as the focus of research is increasing. The studies examined the experienced life of people with disabilities in general (Grue & Heiberg, 2000; Herzog, 2007; Roebroek, Jahnsen, Carona, Kent, & Chamberlain, 2009; Pető, 2018; Cserti-Szauer, Bányai, Katona & Sándor, 2020; Farkas & Petykó, 2020; Langorgen & Magnus, 2020; Witso & Hauger, 2020). A common focus is to map work-related experiences (Krémer & Nagy, 2007; Vedeler & Mossige, 2010; Jakobsen & Svendsen, 2013; Vedeler, 2014; Kuznetsova & Bento, 2018; Csillag, Győri, Kóródi, Svastics & Hidegh, 2021; Csillag, Svastics, Győri & Hidegh, 2021; Wangen & Berget, 2021). Tan, Wilson, Campaign, Murtiff & Hagiliassiss (2019) examined the attitudes perceived by people with disabilities, Jespersen et al. (2018) analysed the impact of social participation on quality of life. Over the past decade, the transition to adulthood has become important (Stewart et al., 2001; Ytterhus, Wendelborg & Lundeby, 2008; Kvalsund & Bele, 2010; Katona, 2014; Castillo, 2018). Tighe (2001) and Hernádi (2014) studied the experience of different body, other studies the experience of femininity, motherhood and parenthood (Hernádi és Köncei 2013; Hernádi 2016; Katona, Heiszer & Szűcs, 2016); Hernádi & Kunt, 2016).

Hästbacka, Nygård & Nyqvist (2016) studied the barriers and facilitators to societal participation of people with disabilities in their scoping review. They found the most studied area is the labour market participation, and 32 studies highlighted barriers related to employment opportunities, workplace environments, and 16 studies identified the adapted working environment, tasks, working hours, supportive employment policies and effective support system as facilitator. The most barriers to participation are attitudes, attention, and missing knowledge of disability. The most highlighted facilitators in the examined studies were legislation, disability policies and support from other people.

We have not found any studies that identified or collected the supportive factors and barriers longitudinally.

This study presents the partial results of a doctoral research. The focus of the research is the identification of factors supporting inclusion based on the experiences and opinions of young Norwegian and Hungarian people with cerebral palsy (CP). Data collection took place between October 2019 and December 2020. Life history and timeline interviews were recorded during the data collection, of which only the results of the timeline interviews are currently presented.

The research is based on the principles of disability studies (DS). The DS approaches from the perspective of the social models of interpretation of disability (Goodley, 2017). The social model is contrast to the previously almost dominant medical model, which saw disability as a “mistake” that needed to be corrected. The social models do not see disability at an individual level but as a social issue (Barnes, 1992, 1999; Shakespeare & Watson, 2001; Köncei & Hernádi, 2011; Shakespeare, 2018). The disability is a complex phenomenon, its examining requires a complex

approach, not a single perspective. The DS does not focus on disability but on people with disabilities, who are the most relevant source of knowledge about disability (Könczei, Hernádi, Kunt, & Sándor, 2015).

The inclusion of people with disabilities is a much-researched topic, but the focus of research is usually on the existing barriers and their possible removal. We have little knowledge of the lives of people with disabilities who, despite existing barriers, study, work, live an independent life, find a partner, raise a child, that is, live their lives like everyone else. The literature typically separates childhood and adulthood inclusion, and there are few studies that put the whole life story in focus.

The basic idea of the research was given by this gap, and it undertook to find people who have a positive view of their own participation and opportunities and who share their experiences and opinions. In this study, we share the very little part of the results, we focused on the visualised timeline only. We examined what events are identified facilitator or barriers and how they change at different ages.

Cerebral palsy

The CP is an umbrella-term that caused by damage to the nervous system at an early age (Bax et al., 2008). Nowadays it is identified as a complex disability in contrast to previously physical disability, emphasizing that the motor dysfunctions are never the single difficulties in the life of people with CP. "The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder." (Bax et al.) Supplementing this definition with our own research position that we do not classify people on the bases of diagnosis, we consider participants in our study as people with different support needs.

Participants

20 participants with CP (6 Norwegian, 14 Hungarian) were involved in the research. 4 Norwegian participants asked to take place the timeline interview at the next meeting, which failed due to the COVID19. 1 Hungarian participant indicated that she did not want to highlight anything from the events told in her life story. She felt, all the events told were equally significant. 1 participant rejected the timeline interview. In summary, 2 Norwegian and 12 Hungarian participants' timelines were generated and analysed. Due to the low number of Norwegian participants, no comparison was made between the two countries.

Highest completed level of education	secondary education: 4 persons	higher education: 10 persons		
Employment status	full time job: 5 persons	part-time job: 6 persons	no job: 2 persons	at home with her baby: 1 person
Typical transport	independently: 3 persons	stick-users: 5 persons	wheelchair-users: 6 persons	
Other difficulties	indicated: 13 persons	not indicated: 1 person		
She/he lives	alone in apartment: 5 persons	with a spouse/partner: 7 persons	with parents: 2 persons	

Table 1 *Characteristics of participants*

Method

Timeline interview

Life story interviews are very popular among qualitative researchers, in which participants are asked to tell stories about their lives. In recent years, qualitative methods have evolved significantly and shifted from standard interviews to more creative tools to get closer to participants' experiences and opinions (Berends, 2011; Ravn, 2019).

A timeline interview is a visual representation of the telling stories, giving participants the opportunity to rethink, clarify, summarise, or even change what is being said (Adriansen, 2012). It helps to reinterpret and select key-moments, helps the author to gain a deeper understanding of the lives of the participants, and thus makes the interview more effective. The timeline interview involves participants in the first step of the analysis thus breaking the traditional research-participant power relationship and empower the participants. The created knowledge is common knowledge of the participants and researcher (Adriansen, 2012).

Also in our research, the timeline interviews were recorded after the completion of the life-story interviews. Thus, the participants not only got involved in the first step of the analysis, but also had the opportunity to supplement and modify the previously told stories and opinions.

After the life-story interviews, we asked participants to mark on the timeline the events that they felt had the greatest impact on inclusion, acceptance, and participation, so on their social position. We also asked them to justify their choices. We divided the timeline into 4 parts based on age: 1) early age (from birth to 6 years), 2) school age (primary school, from 6 to 14 years in both countries), 3) adolescence (between the ages of 14 and 18-19) and 4) adulthood (after the secondary school). The timeline interviews were audio-recorded and transcribed verbatim, thus ensuring a content analysis.

Events that are considered positive impact are referred to as supportive factors, while events that are considered negative impact are referred to as interfering factors in this study.

Analysis

The first step of the analysis was classifying into categories the noted events. We used the same categories that we developed with open coding during the analysis of the life story interviews. The system of the categories is shown in Figure1.

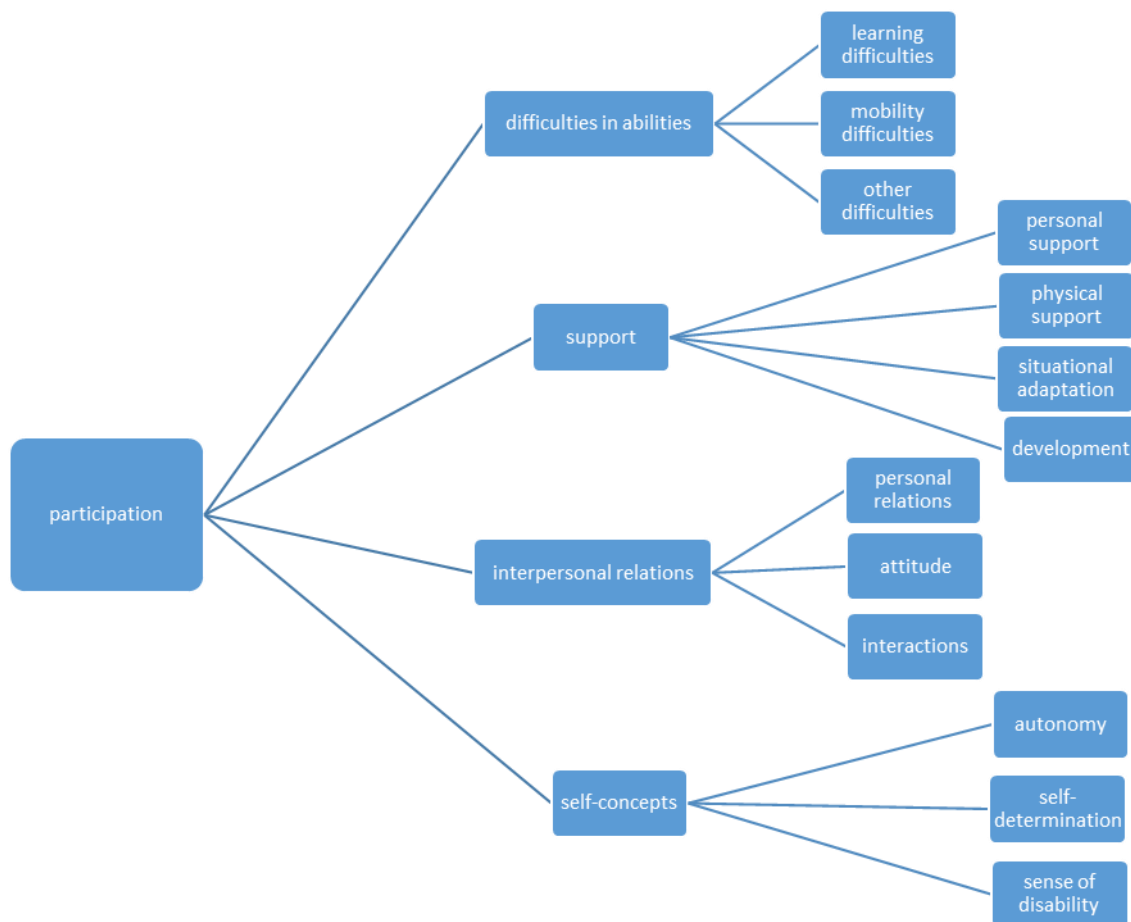


Figure 1 *The system of the categories*

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

- 1) 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: 1) learning difficulties (typically difficulties in reading, writing, or counting), 2) physical disability and 3) other difficulties, such as sensory impairment, depression, panic attack, orientation-, attention, memory problem, difficulties in communication or in speech etc.
- 2) Support. We evaluated the types of assistance mentioned by participants. Within the category the collected data were organized into four subcategories:

- 1) personal support, 2) physical support, 3) developments, and 4) 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).

RESULTS

All the 4 categories were marked as supportive and as interfering factor on the timelines.

First, we looked at how mark of supportive and interfering factors is distributed at ages (figure 2).

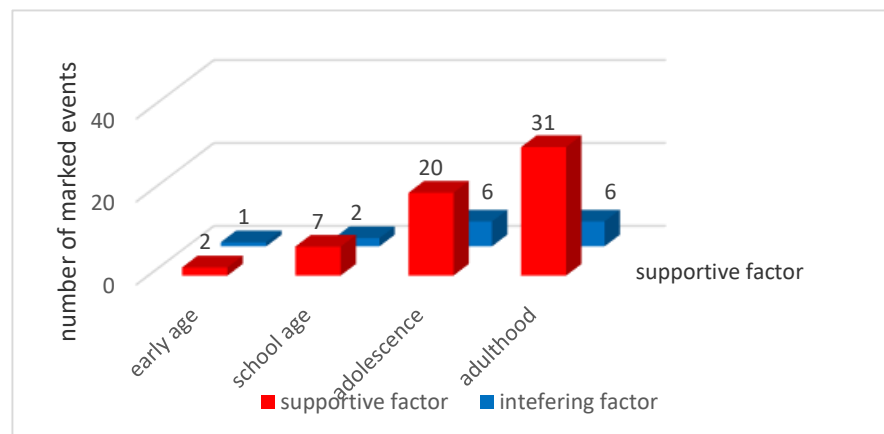


Figure 2 *The number of supportive factors and restrictive factors on the timeline at ages*

It is prominent, the mark of supportive factors is significantly more common at all ages, and the number of marked events increasing significantly in adolescence. The role of supportive factors in adulthood continues growing, and the number of interfering factors does not change. Some of the participants stated that some difficulty had an effect, even strong effect on their live at that time, but this effect lost its significance by now. In their view, overcoming obstacles is more important because it gave them positive reinforcement and thus even identified a negative event as a supportive factor in retrospect.

Supportive factors

The order of the category based on the number of marked events as supportive factor is shown in Figure 3.

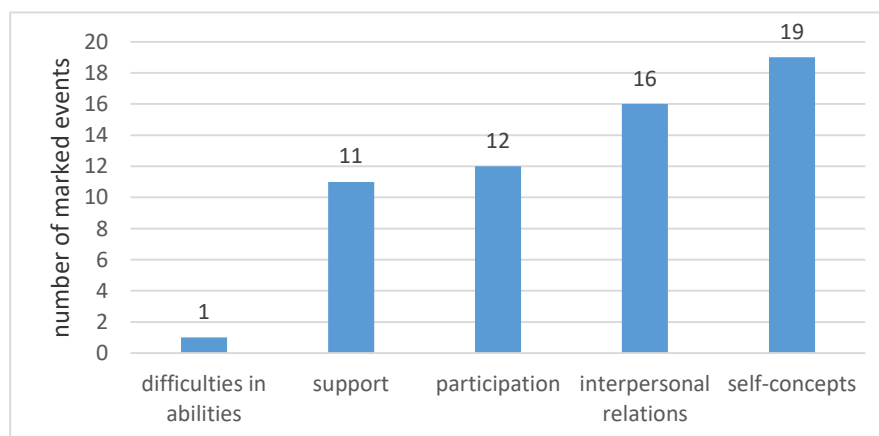


Figure 3 *The number of supportive factors by categories*

The greatest number of supportive factors were made in the category of interpersonal relations (19 marked factors), and all these 19 factors are linked to the social relations subcategory. Thus, the participants most often marked loving relationships as a factor supporting their social position. The loving relationships provide a positive, secure background for participants and emerge as their own, mobilizable resource.

In terms of the number of marked factors, the second in a row is the self-concepts category (16 marked factors), of which two subcategories were coded: autonomy and self-determination. The sense of disability subcategory is missed. This absent can be explained by the view often expressed in life story interviews that recognizing and accepting one's own barriers is a process that has been going since birth and is less linked to events.

The category of participation (12 marked factors) came in third, which means the marking of various leisure, chosen activities in the timelines, and in two cases the "university milieu".

Almost the same number of marked factors in supports category (11 marked factors). Three subcategories were coded as supportive factors: developments (only out of school habilitation developments were mentioned), personal support (personal assistance, „good“ teacher) and physical support (eye-coordinated computer).

The category of difficulty in abilities placed last (1 marked factor), which in this case means a significant improvement in physical condition.

In order to examine whether there is an age specific in the mention of the supportive factors, we examined the appearance of the categories and the number of the categories (figure 4).

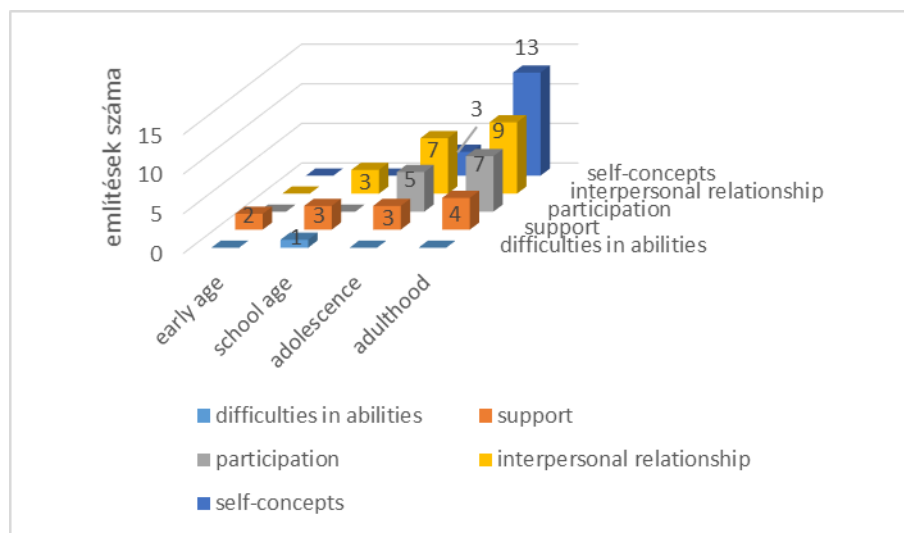


Figure 4 The number of categories as supportive factor by age

At an early age, only the support category was named, 1 participant marked his personal assistant who was with him in the kindergarten (personal support subcategory), and 1 participant considered his habilitation development to be significant (developments subcategory).

At school age, the support category and the interpersonal relationships category received the same number of marks (3-3 marks), and the difficulties in abilities category received 1 mark. In the supports category, 2 people indicated their (out of school) habilitation development (developments subcategory), while 1 person indicated his personal assistant at school (personal support subcategory). In the interpersonal relations category, 2 participants marked her/his relationship with her/his peers as supportive factor, and 1 person marked her relationship with her mother (personal relationships subcategory).

In adolescence, the most mark was in the interpersonal relationship category (7 marks), of which 1 person marked her relationship with her mother (personal relationships subcategory), while the other 6 marks referred to relationship with peers. This result is in line with the age-specific feature of developmental psychology that peer relationships are becoming paramount importance at this age (Cole & Cole, 1996).

At this age appearance the participation category (5 marks) and self-concept category (3 marks) as new categories in line of supportive factors.

The participation category showed a strong correlation with interpersonal relationships category. On the one hand, they emphasized their positive relationship with their peers in school and they were involved in chosen activities, so they spent more time at school with their peers than was compulsory. On the other hand, participants who were marginalised in school at this age and therefore had limited participation in school processes marked out of school activities. They did not necessarily form close relationships in these activities either, but their participation was ensured, and thus – unlike the school – they did not feel outsiders or excluded in these activities. This was one important point, when the interfering factors – marginalisation, lack of relationships – were not marked, instead of them the solution – involvement in out of school activities – was marked as a supportive factor.

In all 3 marks in self-concepts category were related to becoming independent, to independence from the parents (autonomy subcategory) at this age, and it becomes even more pronounced in adulthood.

In the support category (3 marks), 1 participant marked his out of school habilitation development (developments subcategory), 1 participant named as the turning point in her life when she got an eye-coordinated computer and she got able to keep up with her peers in learning (physical support), and 1 participant marked one "good teacher" (personal support).

In adulthood, the self-concept category is the most often marked as a supportive factor (13 marks). 7 marked events are linked to independence, the final move away from parents (autonomy subcategory), which they considered a turning point in their lives. 6 participants named the increasing of their self-confidence and the experience of their own success as an outstanding event (self-determination subcategory), which were tied to work, except for 1 person. In many cases, moving away from parents created a new life situation that had removed previous barriers. In connection with it, the previously mentioned factor reappeared that the interfering factor was not even marked, but the recovering from the bad situation and coping with it was marked as a supportive factor.

The interpersonal relations category is ranked second place (9 marks), that means they considered important more events related to their independence than social contact. It shows on one hand, the previously dominant role of peer relationship is declining and the mention of the personal characteristics' importance and the emphasising of their own responsibilities in participation are increasing. On other hand, the mentioned and marked relationship were also changed. The importance of peer relationships (only 1 mark) is taken over by the intimate relationship (8 marks), which occupies a prominent role among the tasks associated with age (Cole & Cole, 1996).

The participation category (7 marks) is shown also a change. Successful university or workplace participation (6 marks) replaces the previously marked participation in chosen activities. The other change is, while the participation category was closely related to interpersonal relationship in adolescence, it got related to self-concepts in adulthood. The participation in university and work was defined by the participants as where they can be success, show their abilities, and thereby their self-confidence is strengthened.

The number of marks hardly changed in supports-category (4 marks), but their content and - especially - connection with other categories did. Two participants marked their habilitation treatment (developments subcategory) and two other the forming the system of personal assistances (personal support). This category connected with self-concept category at this age, all the 4 participants recognised prominent the marked events because it enabled or at least significantly prepared their independent life.

Interfering factors

Firstly, we also set up on order based on the number of marked events as interfering factor (Figure 5).

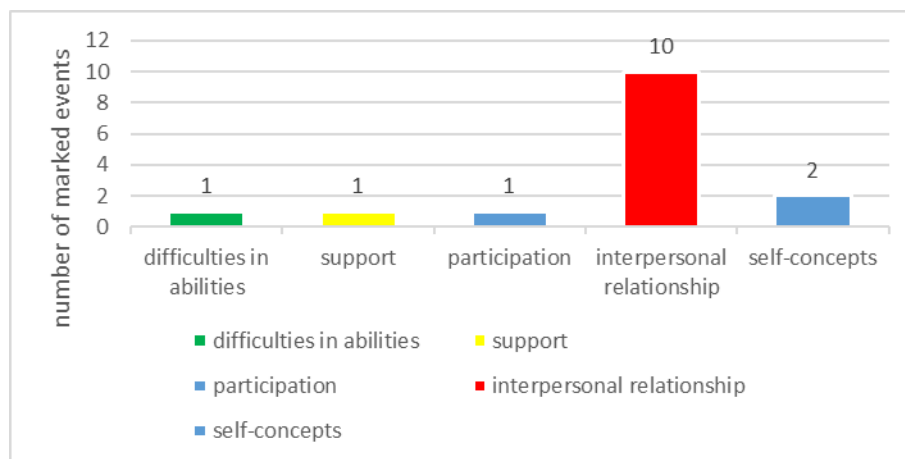


Figure 5 *The number of marked events*

In overall, the interpersonal relationship category is prominent (10 marks), that is, most participants consider the negative relationship or the absent the relationship with peers in adolescence (5 marks) and the personal losses experienced in adulthood (5 marks) to be the most interfering factor in their social position, in the inclusion. There are very few marks in the other four categories: 2 events were marked in the self-concepts category, and 1-1 event was marked in the support and participation category.

The next step was to examine of the number of marks by age (Figure 6).

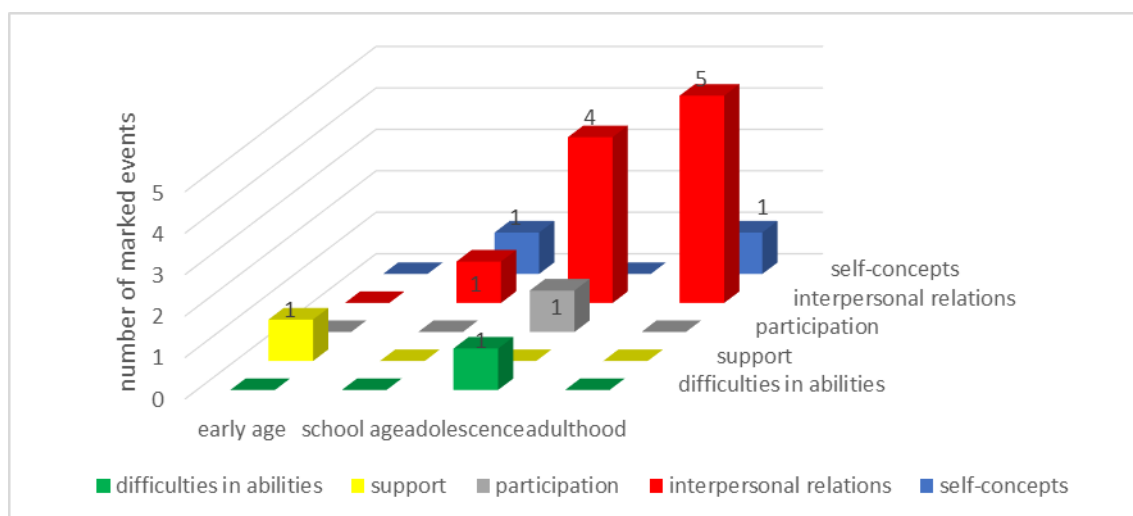


Figure 6 *The number of marked events as interfering factor on the timelines by age*

It is shown again – although less pronounced due to the low number of marks –, there is an inequality in the distribution already mentioned for the supportive factors: the marks increase with age.

There is only 1 mark in early age: it was a painful habilitation treatment (development category) that the participant is reluctant to remember, and in his opinion the treatment set back rather than facilitated his development.

1-1 mark were received in the interpersonal relations and in self-concepts category at school age. 1 participant marked bad relationships with her peer and

teacher in the school as a barrier (personal relationships subcategory). The other 1 participant learned in a segregated school for 6 years, in relation to which he expressed anger at closure due to his disability as a barrier to inclusion (sense of disability subcategory).

The most marks were received in the interpersonal relations category in adolescence (4 marks). All the 4 marks mean marginalisation in the school, the negative relationships with peers or the absent of the relationships with peers (personal relation subcategory). 1 mark was in the participation category, 1 participant excluded from all events in the dormitory. Also 1 mark was in the difficulties in abilities category: 1 participant was forced to repeat the class due to learning difficulties.

The most marks were in the interpersonal relations category also in adulthood (5 marks), and in addition, only 1 mark was made in the self-concepts category. In line with the results obtained for the supporting factors, the prominent role of relationships with peers disappeared in adulthood, and the loss of relationships takes its place as interfering factors in the interpersonal relations category: breakup in an intimate relationship, deteriorating relationship with parents, and death of a child. The 1 mark in the self-concepts category related to the Covid19, which had forced suspending the already established, independent living of the participant and moving back to her parents.

Summary

Many participants expressed related to timeline interview that it mean a new perspective for them and its use was considered positive.

The events marked as supportive factor were significantly more common in the timelines. Based on the explanation of the participants, timeline interviews opened a new perspective, and many of them re-evaluated important events in their lives. From the new perspective, the emphasis has sifted, the barriers were important at that time, but their importance has diminished or disappeared retrospectively. It has become more important to overcome obstacles. Typically, marks in the participation category, as well as marks related to their independence (self-concepts category) often represent a successful way of coping or overcoming obstacles.

The marks increasing by age in the timelines, and a typical pattern emerges. The number of marks of relationships with peers are significant in adolescence, that is, the most events marked as a supportive or an interfering factor are peer-related. The events in the participation category started also in adolescence, and its marking as a supportive factor is closely related to relationship with peers.

The events related to self-concepts got more important in adulthood. The number of marks in the interpersonal relations category are remained high, but the named relationships show a change. The peer relationships lose their significance, and partnerships take their place. The events in the participation category are related to self-concepts rather than peer relationships in adolescence.

Overall, according to the participants' opinion, 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 is that only 1 event was marked as an interfering 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). However, compared to the age pattern, 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. But 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.

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