

THE FORMAL EMPLOYMENT OF DISABLED PEOPLE IS NOT SPECIFICALLY DETERMINED BY ECONOMIC FACTORS BUT BY DIRECT TECHNICAL ONES OR ULTIMATELY BY SOCIAL INTERESTS AND VALUES. A SOLUTION, NEUTRAL IN ECONOMIC TERMS AND ACHIEVABLE IN TECHNICAL TERMS, TO THE PROBLEMS HINDERING THE EMPLOYMENT OF PEOPLE WITH DISABILITIES AND HEALTH CONDITIONS WOULD BE A REALISTIC TECHNICAL SOLUTION AND ACTUAL EMPLOYMENT, BUT ONLY IF THE SOCIETY MAKING THE RELEVANT DECISIONS AND AIMING FOR THE INCLUSION OF DISABLED PERSONS. IN A PERIOD OF ECONOMIC UPTURN WITH A HUGE EXPANSION OF THE LABOUR FORCE, HIGHER EMPLOYMENT RATES APPEAR NOT ONLY AMONG NON-DISABLED PERSONS BUT ALSO AMONG PEOPLE WITH DISABILITIES AND HEALTH CONDITIONS. HOWEVER, ONCE AN ECONOMIC DOWNTURN OCCURS AND THE DEMAND FOR LABOUR FALLS WE SEE THE APPEARANCE OF GROUPS THAT 'CANNOT BE

EMPLOYED IN A PROFITABLE MANNER'. THESE GROUPS INCLUDE NOT ONLY PEOPLE WITH **DISABILITIES** AND HEALTH CONDITIONS BUT ALSO UNSKILLED WORKERS, LONG-DISTANCE COMMUTERS, WOMEN WITH NO MORE THAN SECONDARY SCHOOL GRADUATION, IMMIGRANTS, THE ROMA MINORITY AND OTHERS, IN OTHER WORDS, ALL GROUPS IN A WEAK SOCIAL POSITION, TO WHOSE DETRIMENT IT IS EASIER TO IMPLEMENT **DISMISSALS**, OR WHO CAN SAFELY BE BLAMED FOR ANY DECLINING EFFICIENCY OF COMPANY OUTPUT. AS FINDING A JOB IS INCREASINGLY DIFFICULT IN GENERAL SO THOSE LABOUR GROUPS THAT ARE UNABLE TO PROTECT THEMSELVES ARE EXCLUDED FROM THE LABOUR MARKET WHILE INTENSIVE EFFORTS ARE MADE TO SERVE THE INTERESTS OF THOSE WHO BENEFIT FROM THIS **EXCLUSION**, WITH THE SUGGESTION OF SOME IDEOLOGY. IN THIS CONTEXT, THE LOSERS IN THIS GAME ARE GIVEN A LABEL TO LEGITIMISE THE SITUATION OR FOR SOME IDEOLOGICAL PURPOSES. LABELS SUCH AS 'LAZY', 'DRIFTER', 'LUMPEN ELEMENTS', OR NEGATIVE PERCEPTIONS OF PEOPLE WITH **DISABILITIES** OR HEALTH CONDITIONS ALSO SERVE TO DISGUISE THE

FACT THAT UNEMPLOYMENT IS ROOTED IN MACROECONOMIC AND SOCIAL INEQUALITIES LYING BEHIND THE DIRECT CAUSES. IT IS OBVIOUS THAT ONLY THOSE IN A VULNERABLE POSITION ARE EXCLUDED FROM THE LABOUR MARKET OR ALREADY EXCLUDED FROM IT. FOR SOME OF THOSE EXCLUDED, DEVIANCE IS NOT ONLY A REASON FOR, BUT ALSO A CONSEQUENCE OF, THE FAILURE OF BOTH THE LABOUR MARKET AND SOCIETY. TO THE SAME EXTENT. WHEN ACCOUNTING FOR LABOUR MARKET SUCCESSES AND FAILURES, PUTTING INDIVIDUAL EXCELLENCE OR FAULT TO THE FORE SERVES TO FACILITATE THE EXCLUSION OF SOCIAL GROUPS UNABLE TO DEFEND THEMSELVES WITHIN THE LABOUR ENVIRONMENT. THIS UPSIDE-DOWN LOGIC IS ALL THE MORE DANGEROUS AS MANY DISABLED PEOPLE, AND GENERALLY ALL THOSE IN A MARGINALISED POSITION, BELIEVE THAT THE FAULT LIES WITH THEM. THE RESULTING FRUSTRATION REINFORCES HARMFUL BEHAVIOUR SUCH AS ALCOHOLISM, CRIME AND VOLUNTARY DROPPING OUT FROM THE LABOUR MARKET. FOR DISABLED PERSONS, EMPLOYMENT MAY CONTRIBUTE TO A LOWER PUBLIC BURDEN IN THE SAME WAY AS WOULD THEIR BETTER SOCIAL INCLUSION. ARGUING FOR THE MANY-SIDED NECESSITY OF EMPLOYMENT, TEGYEY SUMMARISED HIS VIEW AS FOLLOWS: 'IN THE EMPLOYMENT OF THE DISABLED WITH REDUCED WORKING CAPACITY, IT MUST BE ENSURED TO GIVE THEM THE MOST APPROPRIATE JOB OPPORTUNITY DESPITE THEIR HANDICAP, THAT IS, SUCH A JOB WHERE WORKING CAPACITY REQUIREMENT COULD BE PROVIDED TO THE FULL-EST POSSIBLE LEVEL. SUFFICIENT OUTPUT IS ACHIEVED TO ALLOW FOR THEM TO EARN THEIR LIVING ON THE BASIS OF THIS SUBSIDITION, THAT IS, TO DEVELOP WORKING ABILITIES AND FINE-TUNING THOSE AS FAR AS POSSIBLE. ALL THE DISABLED PERSONS' SOCIAL

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Narratives of Struggle

Lifelong Guidance and Future Planning Alternatives for People with Disabilities in Hungary

INTRODUCTION

The issue of all strategic planning in the last fifteen years has been to support lifelong learning activities and the labour market integration of young people with special educational needs, thereby expanding lifelong guidance methodological knowledge and the network of experts and service alternatives. This also presents a challenge in innovation and development strategies for the coming years on both European and national levels (McCarthy & Borbély-Pecze, 2020). However, according to the International Labour Organisation's 2014 report on employment trends, young people with special educational needs are at a significant disadvantage in the labour market in terms of the transition from secondary education, job search, and long-term career development (International Labour Organization, 2014).

Several researchers (Nagy, Grónai & Perlusz, 2013; Török, 2017) assert that career guidance has a key role to play for these young people, given that they have high drop-out rates and low-skills. Their training is often deadlocked in terms of their future well-being.

Numerous researchers (Keszí, Komáromi & Könczei, 2002; Csizik, 2007; Csukonyi, Máth, Medvés & Pántya, 2007; Nagy, 2011; Scharle, 2011; Csányi & Mihala, 2013; Cseh, 2014; Dajnoki, 2014; Szellő, 2015; Galambos, 2017; and Dunás-Varga, 2017) have conducted remarkable, comprehensive research on the employment of disabled people. At the same time, the fact remains that little domestic research has been conducted on this topic with particular regard to the supportive and hindering factors of lifelong guidance and the transition to adulthood. Our work may, therefore, be considered a niche study, as it covers both lifelong guidance and employment, and pays special attention to the individual life paths, the subjective experiences, and the narratives of the people involved in various institutional and service environments.

1. THE THEORETICAL AND METHODOLOGICAL CONTEXT OF THE RESEARCH

1.1. Basic concepts and the theoretical background

Our study can be interpreted in the disciplinary context of Special Needs Education and Disability Studies, but it also uses the literature of diverse disciplines. The research is built on an open central question that we have specified in the sub-research.

The main question of our study is: *What kind of supporting and hindering factors appeared in the lifelong guidance process of students with special educational needs in public education in the various subsystems?* This question is mostly explored through the experiences of various actors, disabled adults and students with special educational needs, so we focused on what they mentioned and thematised in the narratives. The related sub-question in the research was as follows: *What kind of supporting and hindering factors did disabled people experience in lifelong guidance during their life path?* In the present study, we do not mention the additional pillars of the research, which focused on the experiences of professionals and life situations related to people with high support needs.

Based on the *social and human rights model of disability* (Könczei & Hernádi, 2011) our work is permeated horizontally by the support need as an analytical concept. We do not examine the characteristics according to each type of disability, however, and where relevant, we refer to the methodological aspects that can be associated with them. We will discuss in detail whether the systematic assistance arising from the need for support and corresponding to it is realised or not. In addition to the term 'disabled person', we also use the term 'person/student with special educational needs', in accordance with the Public Education Act.

Applying the definition of Borbély-Pecze, Gyöngyösi & Juhász (2013), we describe *lifelong guidance* as a long-term process that supports citizens by complementing lifelong learning 'to be able to tolerate, understand and properly manage the changes that affect them. Well-functioning lifelong guidance as a system of pedagogical, counselling activities and as a social support system helps to maintain the individual's openness to change, and teaches [him or her] to initiate and manage change, to direct their own career, to tolerate the uncertainty of change, and provides individuals with the information, advice and support services they need to make decisions and manage change' (Borbély-Pecze et al., 2013, 35) Successful lifelong guidance involves career development, career information and career counselling activities. Career development competencies include the knowledge of various professions and of the labour market, self-knowledge and the ability to match self-knowledge and professions as well as the ability to acquire and interpret training and labour market information, prepare decisions and deal with the consequences of decisions and changes (Borbély-Pecze, 2010; Borbély-Pecze, Gyöngyösi & Juhász, 2013; Borbély-Pecze, 2016).

Based on theoretical and practical experience, the community of *people with high support needs* and their relatives may be considered a particularly vulnerable group. In many cases, their adult life takes place in an environment that seriously violates human rights, which makes it impossible to develop a self-determined

life (Sándor, 2017, Sándor, 2018b). In addition to the narrower concept of lifelong guidance for work and placement in the labour market, we therefore include future planning and person-centred planning, and the whole life-cycle theory and practice of self-determination (Boban & Hinz, 1999, Mansell & Beadle-Brown, 2012, Sands & Wehmeyer, 1996). That is, we are not just looking at how people can find a suitable profession and job for themselves during the transition from childhood to adult life, but we also include housing issues, planning supporters' networks, the spending of free time, the experience of meaningful activities, and the possibility of interpersonal relationships. We expect the application of these inclusive concepts to enrich our analytical frameworks for other groups as well.

Furthermore, because disabled people generally face many barriers in society regarding planning their future, we also focus on how they can transcend these limits, for which we use the theoretical basis of *resilience* as an interpretive framework. Based on this, we analyse the factors of future planning in the structural, cultural, relational and individual processes of the resilience theoretical analysis matrix, all of which may contribute to supporting or hindering this (Cárdenas & López, 2011). Complemented by a social constructivist approach to resilience, we may examine the sources of supportive and hindering factors within the processes. Resilience in a social constructionist approach means adapting to a challenging situation that results from the interaction of resources between individuals and their environment. This is not a linear but a chaotic, context-dependent, complex, relative relationship between risks and protective factors, in which the lived experiences of individuals are at the centre. This approach favours qualitative methods in resilience research (Runswick-Cole & Goodley, 2013; Ungar, 2004).

1.2. The methodological background

From a methodological point of view, we worked along with postmodern research methodological principles in a qualitative research paradigm. Our exploratory, question-driven work is based on Grounded Theory: utilising the continuous interaction of data collection and analysis, we used our study not to test theories, but to expand and deepen existing information. As a consequence, the creation of the theory is not the endpoint of the research process, but it develops, expands and modifies during the research (Glaser & Strauss, 2006; Strauss & Corbin, 1998). In the qualitative strategy, we did not set the research questions rigidly at the beginning, but new aspects and questions might also appear during the research, the method might be adapted to the needs of the field, and even the results of the research might generate new questions. By using and triangulating several methods, we tried to increase the validity of our research, which basically served to answer the same question by several methods at the same time (Szokolszky, 2004). In qualitative research, abduction arises in the development of the research process, which is a conclusion based opinion or assumption. The conclusions are not based on certainty but are the consequence of a creative leap of thought in which the researcher plays a central role. The researcher starts from his / her preliminary knowledge and subjective observations, from the specific alloy from which the conclusions are formed (Sántha, 2011).

The 'Nothing about us, without us!' principle was implemented using participatory methodology (Barnes, 2009, Marton & Könczei, 2009). Two disabled co-researchers, Dániel Csángó and Károly Tóth, also took part in the entire process of the research, from the preparation of the research plan to the data collection and analysis of the results. With this, the points of view of some disabled people are directly reflected in our study, influencing the research process. As non-disabled, professional researchers, we work not only in what we consider are the best interests of disabled people but also for the purpose of jointly defined goals, valuing the life experiences of those with whom we have conducted the research (Clements, Rapley & Cummins, 1999; Könczei, Antal & Kolonics, 2016; Antal, 2017; Sándor, 2018a). We consider the lived experience and local knowledge of disabled people as having a special value, a kind of special expertise, which complements the acquired knowledge of non-disabled researchers (Heiszer, Katona, Sándor, Schnellbach & Sikó, 2014).

In one part of the research, we focused on individual life paths and conducted semi-structured individual life story interviews with disabled adults regarding their lived experiences. In line with the participatory approach, the interviews were conducted in pairs, in which a disabled and a non-disabled researcher worked together. The literature states that the so-called dyadic, paired interviews can lead to more relevant and valid conclusions in practice (Caldwell, 2014). However, in the part focusing on life paths, in some instances we could not involve a participatory research partner (due to technical and accessibility issues), so we recorded classic two-person interviews.

In our study, we draw on the experience of interviews with five students with *learning disabilities and five physically disabled adults*. The interviews were recorded on a dictaphone and in each case we provided anonymity by using pseudonyms, as well as guaranteeing confidentiality to our interviewees, who signed a consent form. In all cases, the interviews were conducted at a time and place convenient for the interviewees. The length of the interviews was approximately 60 minutes. In the analysis, we focus on the latter two of the structural, cultural, individual and relational factors.

2. RESULTS

The interviews were analysed with a thematic analysis, during which the main dimensions were compared, collecting the similarities and differences. In content analysis, we combined deductive and inductive strategies. On the one hand, we started deductively from an already existing category system, which we matched with the texts of the individual interviews. That is, based on the matrix of theoretical analysis, we coded what was said in the interview according to structural, cultural, relational and individual processes, supplemented by a social constructivist approach to resilience (Cárdenas & López, 2011; Katona, 2014, based on Runswick-Cole & Goodley). The interview excerpts, classified into four main categories, were also grouped according to whether they were perceived as aiding or hindering factors for the interviewees' life path planning. In an inductive way, based on what the interviewees said, we developed the codes that could be classified into four main categories, taking into account the new aspects inherent in the interview texts.

In the course of our analysis, we tried to find similar patterns and matching information in the life paths. We presented our results separately for young people with learning disabilities and adults with physical disabilities. We illustrated our interpretations with interview quotations, and at the end of these texts we used pseudonyms.

2.1. Students' experiences of lifelong guidance

Young people with learning disabilities form one of the groups of students with special educational needs. Their situation is special as the terminology suggests that this category focuses primarily on learning challenges. The question arises as to what kind of learning this is really about. Does it only refer to difficulty in meeting the requirements of the school curriculum and the lack of the necessary abilities and skills? According to the classic definition of the Budapest study (Czeizel, Lányiné & Rátay, 1978), in addition to school performance, this group is also characterised by difficulties in leading an independent life. Important elements of the latter are lifelong guidance, labour market planning and success.

In our research, we sought an answer as to how and by what means vocational schools support lifelong guidance and the *job search of their students with learning disabilities*. During the research, structured interviews were conducted with five young people from Budapest. We grouped our questions around five topics (childhood, school experiences, current relationships, quality of life, and vision of their future). When compiling the set of questions, we placed great emphasis on decision-making and its supportive environment.

We sought the help of two vocational schools and an alternative primary school to find the interviewees. In the vocational schools, the deputy principals consulted with the students about the research before providing us with contact information, but in the primary school, they consulted with the parents. The mother of the interviewee recruited from the primary school recommended her daughter's friend, who is also a young person with a learning disability. During the interviews it later transpired that both of them studied in one of the vocational schools we visited, although the school management had no active relationship with them. Three of our interviewees are women and two men, the youngest being 21 years old and the oldest 28. Each has at least one profession, all work, and one attended a school that provided a graduation certificate at the time of the interview.

2.1.1. Supporting factors in lifelong guidance

During the interviews, we covered several topics, but in this study we describe specifically the participants' experiences of vocational school with regard to lifelong guidance. Lifelong guidance '[...] is a process that helps [students] select the appropriate career and profession, taking into account the individual needs of the student, by providing the widest possible information' (Szilágyi & Völgyesi 1996, id. Borbély-Pecze, 2010, 9). In this sense, the task of career guidance is twofold, as it not only includes imparting knowledge of specific professions and related labour market opportunities, but also awareness of the students' own self-knowledge in the broadest sense. These

tasks are the responsibility of vocational school teachers in close collaboration with those who teach professions.

Table 1. Supporting relational and individual factors (edited by the authors)

Relational	Individual
The family becomes an expert – the ‘struggle narrative’ (optional)	Independent decision making possibility
Family network in job search	Own career plan for the future
Vocational school mentor (optional)	

Factors that support career development at a relational level

Based on the interviews, relational support is an important element of career development.

Parents played a significant role in the career choice and job search of all interviewees.

In the case of interviewees from families with high socio-economic status, parents (mostly mothers) became experts in treatment, schooling rights, and so on. Here, as well, the ‘struggle narrative’ appears on the part of parents as they sought childhood development opportunities, schools, hobbies, NGOs and jobs.

‘My mum and I went to many workplaces. We went to the X Foundation. I didn’t work there, I just walked around. [...] I went to the Z Foundation, [and] I went to another foundation as well. You just had to work in a group home there. And then came the NGO, and so came the job.’ (Betty)

However, in finding a job, every parent supports their child, which in turn means that the vocational schools do not have employee network connections and that students would not be able to find a job on their own.

‘My mum works with me. So I’m a porter, and she’s a nanny in the nursery right there. And then she helped me find a job.’ (Roland)

In the case of interviewees of low socio-economic status, instead of very active parental support, we can see an accidentally formed vocational school mentoring relationship.

‘Well, they knew it was the case (stroke at birth), and they thought, that I’ll make it somehow. But they were always by my side, with all the problems.’ (Hugo)

When selecting the deputy directors, it was also an important factor for the interviewees whether or not they (the deputy directors) had maintained contact with the students after they had finished school. These are not system-wide relations, but are formed randomly. The names of the two interviewees recruited from primary school were not even mentioned by the vocational school as potential interviewees, which means that there was no connection between them.

'Well, he liked it in the ninth grade. And then we were doing well (the school child protection specialist - ed. comment). We always talked a lot. He actually looked at me like I was his son. [...] At that time (when a profession was chosen - ed. comment) I was not in such a talking relationship with him. We only turned to him if there was a problem with the school.' (Hugo)

Mentoring plays a key role in building self-knowledge and self-confidence. As this, according to the interviewees, was random, it can be considered an indirect element of lifelong guidance. Mentoring, if not specifically in the choice of profession, has a positive effect on personal development later.

'I think I said I had a second mum. Yes, because she was so hard too. [...] And she also took me to Baja, to that competition.' (Anna)

The mentoring relationship was not limited to one area at a time, but they also entrusted a number of significant activities to the interviewees (poetry recital at a graduation ceremony, professional competitions, etc.), which improved the self-esteem of students, who became more confident and open-minded.

'It wasn't confusing because I was an excellent student [...] so that's exactly what I was asked to do, to help him in his studies. Well, in the beginning, I wasn't so enthusiastic about teaching a person like him. [...] it would take all my free time. Then I started, so even if he didn't speak, I got excited about the whole thing, [...] I taught him several things. He learned this all because of me. After waiting for the first results to come, I was really pleased that he got good marks because of me.' (Anna)

Factors that support career development at an individual level

As a child, each interviewee encountered a dismissive, abusive attitude at an individual level. They needed considerable support in reinforcing their self-confidence and self-acceptance. The role of vocational school mentors, friends and supportive work relationships came to be of great importance in their lives.

'I grew up and realised that [...] I don't need to, I shouldn't strive to have friends. Because if they want to be my friends, they'll love me the way I am. And then I registered for a dating app, I was already 18 years old. [...] And then a boy wrote to me, he lives in D.n. We agreed on many things, we talked, then met. Since then we've been together for three years.' (Anna)

Two interviewees met their current partner at the vocational school, one also living in a registered relationship with his partner.

'He still loves me. He used to call me on his mobile. I met him at school. And we used to go home together, he used to accompany me to the metro.' (Susy)

'She studies in a vocational school, yes, in the hospitality industry. She still has a year to go. We've been together ever since she started there. [...] We come out well, thank God. We are also fine with my mother-in-law.' (Hugo)

The possibility of independent decision-making means that parents see their child as a partner, which is an important part of growing up.

'They said I was 18, I did what I wanted, and I also worked. And then they said it was OK. But if I don't like something there (at his partner's parents - ed.), I can always come back to them. I can go back.' (Hugo)

The narrative of struggle appears in several interviewees' stories, for example about their education in relation to their parents.

'Well, first Mum told me not to bother her with this nonsense, as, well, this good school surely wouldn't take me with my diagnosis and special needs certificate, because it's really a bilingual school, and it would be so hard for me. But on the other hand, it drove me as much as possible. And I didn't know that Mum had discussed this issue with the director. And she came home one night with this plan, [to] pack [my] stuff the next day and go to this vocational school.' (Anna)

'Well, [...] very much of my own volition. My mother didn't really like it, but I told her I wanted to go in this direction. Because I am sure I won't even go to school if I can't study this profession. Maybe she understood it because then she allowed it.' (Roland)

Hobby activities are also meaningful, when a person is not someone in need of development or support, but is an independent actor.

'It's a really good feeling to support someone (in case of wall climbing - ed.). But there were times when I could handle a 72-kilo person.' (Betty)

It is very significant, with regard to our focus on lifelong guidance and career development, that three interviewees have plans for the future. This is, of course, related to their current jobs and circumstances.

'Well, after graduation, I'd like to get a certificate for a profession. This would be free after graduation. And I want to learn to be a nurse.' (Anna)

'I want to get a license for the forklift truck next year.' (Hugo)

'I was invited to join a support group for people who live in group homes. And there they talk to the residents and the head of the institution. And I thought I could go, too.' (Betty)

Stigmatising personal experiences were thematised by two interviewees. One interviewee tended to have a negative, covert attitude while the other tended to be tolerant.

'Because no one could tell me that it would be the right place for me. [...] That I have no problems with my cognitive functions. There's nothing on a behavioural level either. I only went there because I had this diagnosis and paper about it, and then I had to go there, to the special department.' (Hugo)

'You're developing in your field, and you need to let it develop the way that's good for you. And I don't think we need to evolve with the world. I think it's a characteristic of everyone that they develop at their own level, and not as expected.' (Anna)

2.1.2. Hindering factors in lifelong guidance

Table 2. Hindering relational and individual factors (edited by the authors)

Relational	Individual
Special school environment – aggression in school	Lack of self-confidence due to previous negative experiences
Lack of practical and adult life training at school	Physical and cognitive abilities
De-motivation of professionals, lack of well-trained professionals in the close environment	
Parental opinion	

Factors that hinder career development at a relational level

The influence of families, especially mothers, is decisive at a relational level. Only two interviewees made explicit criticism.

‘They said it would be completely different in a normal class. Because they said I’d definitely fail there.’ (Hugo)

‘It was Mum who really wanted me to study this. It was free. A profession with a higher degree and a graduation, I’m expected to earn a little better than her or anyone else. I don’t want to work in my profession.’ (Anna)

Although almost all interviewees claim to have loved the vocational school they attended, they independently stated that aggression and drug use were present in the school.

‘That’s why drugs were here, wasn’t it? They gave them to each other.. There were times when I also took my bag to the loo so they wouldn’t put anything in it, so there would be nothing. And phone thefts have gone up a lot here.’ (Anna)

‘They were picking on me in my previous school, but I didn’t want to tease anyone, only because my classmates did that.’ (Roland)

Factors that hinder career development at an individual level

The interviewees’ previous experience of the negative attitudes of colleagues is decisive at an individual level. All the interviewees greatly appreciated their current jobs because they were accepted there. They tried to do everything to keep their jobs, in many cases by taking too much on themselves.

‘There are times when we have too much work. We don’t have enough room. Then I come in to make some room, but I also call my boss to let her know that I’ll come back in the evening.’ (Hugo)

Interviewees also described physical or other limitations that made it difficult for them to choose a profession or a job, or to manage their daily lives.

'The other is textile production. I couldn't go there because of my health [...] You always have to calculate how much it costs. You have to part with money. That's why I went back to the other profession.' (Susy)

2.2. The life pathways of disabled adults

The interviewees were selected by expert sampling, which focused on the following criteria:

The participants are engaged in activities that are considered significant; they started 7th grade of primary school in 2007 or later; and they have received (in a broader sense) lifelong guidance.

Based on this, five *physically disabled adults* with were interviewed, two women and three men.

2.2.1 Supporting factors in lifelong guidance in the narratives

We first collected the recurring contributing factors in the narratives, which we systematised according to structural, cultural, relational and individual processes, and in this article we show the results of the relationship and individual processes of these. In summary, resilience, overcoming the disadvantages of disability, and overcoming barriers were aided by the following factors based on the experiences of the interviewees (see *Figure 3*).

Table 3. Supporting relational and individual factors with regard to disabled adults (edited by the authors)

Relational	Individual
Active lobby activity of the family, parents becoming experts – 'struggle (of the family, mainly the mother) narrative'	Feeling of power and control – 'struggle' (of the disabled person) narrative'
Encouraging self-determination (rather in the family)	
Strong relationship network	
Inclusive school environment	

Factors that support career development at a relational level

Most of the contributing factors were described at a relational level by the interviewees.

Among these, the most common point in the narratives is a very strong, supportive family background, when the activity of their parents (especially the mothers) is striking.

'And so when my mum came up with the idea of a disabled [child] going to this sports school, well you know, she came up against a wall. And my mum pushed until she even said it was good, okay, [the school could] give [him] a week, a week and a half to get to know [him]. And if we see, well you know, that it's not going to work for him, we'll really stop. And this deputy principal was constantly against it. And in a week and a half, I was practically integrated with the others at that level.' (Robert)

Interviewees frequently mentioned finding an accessible school or finding a suitable profession in which parents also played a significant role.

'And that's when the idea came up that my mother would start looking for accessible schools [...]. And Mum thought that if I tried this law-related [school], not as a lawyer, but still in the line of legal administration [...]. Well, overall, I'm basically satisfied, because I think what could have come from me, what I could have become, pretty much happened.' (Benjamin)

This result corresponds with the results of a previous study, in which one of the dominant strategies in relation to the adulthood of people with disabilities was that parents lifted the barriers facing their adult child (Katona, 2014). This often includes strong lobbying by parents and their playing a significant role in their child's career choice and employment. Parents take this role so seriously that they become experts in the field of disability. We have called this a 'struggle narrative' in the interviews, when this struggle focuses on the family.

'No, the expert was my mother. And then I went for the second degree. So we have educated ourselves so much on this subject. And we laughed when somehow it turned out we knew better.' (Emma)

Support for the family, on the other hand, is more manifested in encouraging their child's self-determination, which is also a typical but less common strategy in previous research (Katona, 2014).

'My mum played a big role in the story because she didn't butter the bread for me, but she taught me how to do it. And I started my life with this philosophy.' (Robert)

There were those who were specifically raised to fight as they saw that this was the only way a disabled person could prevail.

'So they (my parents) said you have to fight to be accepted. And then maybe if you make yourself acceptable, you can expect them to give something too. And that seemed completely unfair. But looking back, it kind of turned out to be useful because I started to come up with a lot of strategies to make me acceptable.' (Emma)

Several mentioned that the family basically supported their idea, not holding them back from their goals.

'Because yes, my parents were the ones who never insisted but supported me... They handled it pretty well. They raised their eyebrows a little [...]. But then they realised that this was important to me, it was a good opportunity. So they were basically supportive.' (Emma)

The parents were not only supportive in motivating them to learn, but also, if they could afford it, in aiding further learning by paying for private lessons.

'Well, for us, that was basic. So this has been pushed into me, that speaking a foreign language is basic.' (Stella)

Aside from this, some reported that their disability was not an issue, and that they were not treated differently.

'And my whole family, basically, didn't see my disability in me, I was treated like a completely normal child. And that sometimes gave birth to oddities. At the same time, however, they were aware of my difficulties. They just really didn't give much importance to it, so as not to deal with it differently.' (Benjamin)

Several emphasised that the integrated educational environment also had a supportive effect on their plans for the future, which could even be at a structural level, but as personal relationships play a more prominent role here than the system itself, we have listed this, but not categorically.

'Well, I went to a normal nursery and to a normal school. Which was very, very lucky in that sense, because I wasn't, so to speak, segregated from society, but together we were able to relax, fool around and learn what we had to as a normal young person. And so I wasn't like that, I wasn't discriminated against, but I also grew up as a healthy kid. And it helped me a lot to be more aware. And so I have a purpose in life, even if I'm disabled.' (Robert)

'[...] and there I went to primary school with normal kids. Which is a dubious thing, isn't it, at the age of seven? To get into a school with non-disabled kids as the only disabled person. Because the kids could either accept me, and I'd be the centre of attention, because I was different from the others, or they wouldn't accept me, for the same reason. Fortunately, the former happened.' (Benjamin)

In several interviews, participants mentioned the highly motivating, supportive personalities of one or two teachers, who also helped build self-confidence and preparation.

'In secondary school, however, my teachers saw something in me. And they basically helped me, prepared me for graduation, even for higher level graduation... And this extra time he spent on me between breaks, in his free time.' (Emma)

Supporting factors in lifelong guidance at an individual level

At an individual level, the 'narrative of struggle' refers only to the disabled person and not to a family member, which stems mostly from a sense of power and control.

This can manifest itself in the workplace.

'There are very, very many, complex tasks. So, that's why I was happy, because it can be a little better for a person, for a person's health, when they are already entrusted with tasks that, for example, not everyone can handle. So plainly speaking there is a weight on your shoulder [...]. And it gives you energy. That's a good thing for my self-esteem.' (Robert)

It is often a great realisation that they do not have to wait for others to make a decision, but they can decide for themselves.

'But that, for example, when I was looking for a partner, I had a great realisation that, oh my God, I don't have to choose whoever chooses me. I can choose for myself too.' (Emma)

There were people who explicitly identified themselves with the struggle narrative.

'Well, it's an inner narrative that I may not be able to identify with. Because there is this narrative that the whole life of a disabled person is a struggle. And that's how we describe our lives.' (Emma)

This personal empowerment may act as a significant driving force, which is clearly related to how parents perceived the individual at the relationship level, and the degree to which they strengthened their sense of competence and self-determination.

2.2.2. Hindering factors in lifelong guidance in the narratives

Table 4. Hindering relational and individual factors with regard to disabled adults (edited by the authors)

Relational	Individual
Segregated school environment	Feeling of incompetency, lack of self-confidence
Lack of teaching practical and adult life skills in the school	
Demotivation of professionals, lack of well trained professionals	

Hindering factors in lifelong guidance at a relational level

At a relational level, the attitude of the family can also be a hindrance, but our interviewees experienced more support in this area.

However, there were negative experiences regarding some professionals, and even the lack of expertise of the life path coach mentioned earlier can be partly attributed to this.

There was a lack of instruction in preparation for life on the part of some teachers.

'We did not teach life skills. Maybe none of it. So how to get along in life or how to tackle certain things. None of it.' (Stella)

In some respects, the attitudes of classmates also proved to be a hindrance.

'There was no encouragement, so no one in our class wanted to study further. At the previous school I came from, there was a 98% rate of further education. So it would have been good anywhere in between [the two schools]. And everyone graduated there with an 'A', while no one had any plans for the future in our class. Maybe I had the most [plans] in the class. [...] I had a classmate who didn't even graduate, there were even two of them! And so I can imagine that he didn't have many plans.' (Benjamin)

'I hated school in the beginning because my classmates were picking on me a lot.' (Arnold)

Hindering factors in lifelong guidance at an individual level

On an individual level, the aforementioned power and control was not always in the hands of the same interviewees, implying that they lacked sufficient self-confidence or were faced by an identity crisis. So at some stage in their lives, these also appeared as a hindrance.

Sometimes basic physical and contextual constraints made it difficult to choose a career and continue with one's life.

'On top of that, I also felt I couldn't stand it physically. So I also felt that what I was choosing was very selective.' (Emma)

CONCLUSIONS

In our study, through interviews with five students with learning disabilities and five physically disabled adults, we presented the supporting and hindering factors of lifelong guidance at a relational and an individual level.

At a relational level, the supporting role of the family in both groups is important in terms of school search, labour market placement, strengthening self-determination and motivation. Furthermore, for some of the interviewees, a teacher played a resilient role, but the development of these mentoring relationships is not systematic. At an individual level, partly as a result of the above mentioned results, a sense of control over their own lives and the ability to resist power are supporting factors. Among young people with learning disabilities, a definite vision of future labour market trends is an important element of career development.

Deficiencies in school career development were mentioned by both groups, such as lack of practical preparation for adult life and person-centred planning, and poor levels of motivation among the professionals concerned. We also consider the continuous support of school professionals involved in career development (for example through training sessions, development workshops or forums to facilitate the exchange of experiences) and the utilisation of their experiences to be of paramount importance. Therefore, based on the experience of the research, two types of training contents were developed. One of the directions is the involvement of special needs teachers attending Bachelor's and Master's programmes in the implementation of lifelong guidance with a modern approach. The *'Carry on! The preparation of teachers supporting lifelong guidance and future planning for children with special educational needs and disabled young people'* further training programme provides opportunities for providing teachers already working in schools with resource-focused knowledge. At an individual level, a lack of self-confidence in both groups is a basic, common experience. In the case of physically disabled adults the feeling of incompetence was thematised as a hindering factor, while young students with learning disabilities mentioned barriers arising from physical or cognitive abilities. Overall, based on the interviewees' experience, individual and relational barriers (family, peers, or society)

may be reduced and personal resilience may be increased by the family, the 'struggle narrative,' and / or school support person's mentoring role.

Our results will be nuanced in further publications by the supporting and hindering factors presented at structural and cultural levels that also determine the system-level framework.

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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 PROVISIO 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 AN 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 MEETING SPECIAL NEEDS EDUCATION. THE 1991 LAW ON EDUCATION RECOGNIZED THE RIGHT OF CHILDREN WITH SPECIAL NEEDS TO BE EDUCATED IN SCHOOLS CLOSEST TO HOME. SINCE 1991 SCHOOLS STARTED USING MORE RESTRICTIVE CRITERIA FOR ACCEPTING CHILDREN INTO SPECIAL SCHOOLS — A CRUCIAL GATEKEEPING FUNCTION. AMENDMENTS IN 1998 SET OUT 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

