Eötvös Loránd University Faculty of Education and Psychology
PhD School of Education
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PhD Dissertation Summary

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The social aspects of the transition to adulthood of people with physical disabilities

The possibility of their acquiring resilience in the course of their lives

1. INTRODUCTION, RESEARCH PROBLEM

The UN Convention on the Rights of Persons with Disabilities declares the fully valued active role of people with disabilities in society. Article 19 emphasises the question of independent living and participation in community, which is the embodiment of social inclusion (UN, 2006).

Social inclusion is the realisation of the fully valued, adult role of people with disabilities. According to the UN Convention, society has to provide people with disabilities the optimal conditions for making the transition to adulthood and participating in society. However, we also have to take the individual conditions into consideration, because when it comes to human rights, people with disabilities have to take action and sometimes have to fight for their rights (Kőnczei, Hernádi, 2011). People with disabilities encounter many risks and social barriers during the transition into adulthood (Janus, 2009; Trainor, 2010).

Acquiring resilience could provide a solution to meeting these barriers in society. Resilience involves stepping over one’s delimitations and showing flexibility and buoyancy. Yet this is more than a psychological factor, and we can describe resilience with regard to the interaction of individual characteristics and social systems (Herrman et al., 2011). The personal characteristics and the social factors ensure together the resources of resilience. The risk factors and compensatory factors are derived from both internal and external resources (Waxman, Gray, Padrón, & 2003).

The number of people with physical disabilities has grown in Hungarian society, and they are the largest community of people with disabilities in the country (KSH, 2011). We consider the situation of people with disabilities as an "accumulator lens". Their lived experiences accumulate and reveal special aspects of transition to adulthood and resilience which do not appear when examining other groups (Waldschmidt, 2012).

The status of people with physical disabilities in society is depend on the requirements made by society, so their social roles are important, but we also have to take into consideration the identity of the individual.

The social roles of people with physical disabilities are often described according to the requirements of dependency, passivity which have a negative influence on the transition to adulthood and impose upon them the role of a child, of a patient or one of permanent post adolescence (Katona, 2010; Krémer, 2011). We would like to raise the question as to how people with physical disabilities may adopt an autonomous, adult role, contrary to social expectations.

Family socialization and the attitude of the parents are relevant factors, because these represent prime mediators between the individual and society (Goslin, 1986; Nagy, Trencsényi, 2012; Somlai, 1997). We are looking for supporting and restrictive factors in all areas of life as elements of resilience. We suspect that the attitude of the parents to their children with physical disability may have an influence on their acquiring resilience. Having an autonomous adult role may contribute to a successful transition and thus the dimensions of social adulthood may become apparent in the course of their lives.
2. THEORETICAL BACKGROUND

To interpret this complex situation regarding people with physical disabilities we could collate the various experiences according to different theories. In a qualitative approach the researchers have to find their own improvisation and patchwork of the applied theories and methods to match their research aims (Denzin, Lincoln, 2011).

Interpreting the experiences of people with disabilities within the uncertainty of our postmodern world we need eclectic theoretical discourses and practices with a holistic approach to disability (Könczei, Hernádi, Kunt, & Sándor, 2014).

The basis of our patchwork is the discipline of disability studies, which allows us to combine different theoretical frames, methods and schools as well as descriptions of postmodern reality (Nagy, Könczei, & Hernádi, 2009). In disability studies people with disabilities not only comprise the target groups of examinations, but they are also active participants in research, based on the principle of 'Nothing about us without us' (Marton, Könczei, 2009).

Interpretivism is also a determinant in the patchwork, as we emphasise how people interpret the world and how they map the social elements in their lives. We can understand a society best if we examine the lived and interpreted experiences of its members (Goodley, 2011). Within the interpretive paradigm there are a number of schools of thought, which we have mixed and included in our research. Applying the principles of hermeneutics we have interpreted the texts of interviews and the investment of purport happened in the hermeneutic circle from the parts to the whole and from the whole to its parts (Kvale, 2005).

Applying the principles of phenomenology we seize the substance via the lived experiences of the people we studied (Hernádi, 1984).

The approach of symbolic interactionism also appears: the individual’s interactions with their social world and the direct environment have great significance in the development of the social role and identity of disability (Némedi, 2005).

Constructivism is also a determinant in the interpretation of disability as a social construction and in the social constructionist approach to resilience (Runswick Cole, Goodley, 2013), in which we focus on the construction of supporting and restrictive factors in their given contexts, as well as on how people with physical disabilities experience these in the course of their lives. We have combined the social constructionist approach to resilience with the resilience theoretical analysis matrix in which we can place the lived experiences of resilience in a system (Cárdenas, López, 2010).

In the theoretical part of the dissertation we touch upon relevant areas with regard to the research problem. After describing the target group we concentrate on the requirements stated in the UN Convention, reviewing the background to the convention and the degree to which it is implemented (Bass, 2011; Magyar Civil Caucus, 2010; Horváth, 2013; Zászkaliczky, 1998 etc.). Then we define self-determination and independent living in the lives of people with disabilities (Mithaug, Mithaug, Agran, Martin, & Wehmeyer, 2003; Wehmeyer, Gragoudas 2004; Wehmeyer, 2005; Zalabai, 1998 etc.), and, with regard to both these states and the process of transition to adulthood, we show the importance of family socialization (Garai, Kovács, 2014; Nagy, Trencsényi, 2012; Rozsos, Krémer, 2009; Somlai, 1997 etc.). We reveal that in society the main socialization agents require mostly dependent, passive roles from people with disabilities. Family socialization is the main mediator between the roles required by society and identity in people’s personal lives, so it is relevant whether the family meets the requirements of playing a dominant role or not. We show that it is possible to identify the interference of identity and socially ascribed roles in people’s life.
stories (Assmann, 1992; László, 2003; McAdams, 1988; Ricoeur, 1999 etc.). Our study continues with an interpretation of social adulthood and post-adolescence (Janus, 2009; Murinkó, 2010; Trainor, 2010; Vaskovics, 2000 etc.), after which we examine the various definitions of resilience (Cárdenas, López 2010; Herrman et al. 2011; Pinkerton, Dolan, 2007; Runswick Cole, Goodley, 2013 etc.). Finally we highlight possible factors that may correlate with having an autonomous adult role, and eventuate resilience based on professional literature (Alriksson, Wallander, & Biasini, 2007; Berszán, 2008; Nagy, 2014; Osgood, Foster, & Courtney, 2010 etc.).

3. RESEARCH QUESTIONS, ASSUMPTIONS

Research questions

- How does society delineate the social adulthood and independent living of people with physical disabilities?
- How do people with physical disabilities know their way around in the social frames? How are social adulthood and independent living realised in the course of their lives?
- How is the transition to adulthood supported? In what ways can this be restrictive?
- How do family socialization and parental attitudes contribute to people with physical disabilities attaining some level of social adulthood and independent living?

Assumptions

1. Contrary to the requirements of UN Convention, people with physical disabilities encounter many social barriers regarding the transition to adulthood and independent living. For these people, Article 19 of the convention is only realised at a low practical level, external obstacles (threats) having more significance than internal weaknesses (SWOT analysis).
2. In the lives of people with physical disabilities transition to adulthood has no fluency, and they experience difficulty in overcoming social barriers created, so the period of post-adolescence may be extended, or they could remain in permanent post-adolescence. To move on from this socially determined post-adolescent status they need to develop strategies for building resilience.
3. The capacity of people with physical disabilities to acquire resilience and resistance to social barriers depends significantly on the attitude of the parents to their child, which may influence the dimensions of their social adulthood.
   3.1. If the parents treat the person with physical disabilities as a child, and the parents have an authoritarian attitude, the person’s level of resilience will be lower, resulting in a lower level of social adulthood, and, typically, their having a post-adolescent status.
   3.2. If the parents treat the person with physical disabilities as an equal, and the parents have a ”democratic” attitude, the person’s level of resilience will be higher, resulting in a higher level of social adulthood, and, typically, their having an autonomous adult role.
   3.3. If the parents accept the status of their child with physical disabilities, the person’s level of resilience will be higher, resulting in a higher level of social adulthood.
4. The local environment also has an influence on resilience, those interviewees residing in the capital or in its outskirts being likely to encounter fewer obstacles, with the result that internal, individual compensatory factors have a greater impact on resilience, and they resort to less external (family, environmental) support. Those interviewees living in the country are likely to encounter more obstacles, with the result that internal, individual factors are not sufficient, and external (family, environmental) supports carry more weight.

4. RESEARCH METHODS

As we are interested in the problem at a deep level, we applied qualitative methods. The research is not concerned with generalization, the aim being rather to discover and understand the social phenomena in the context of the subjects’ lived experiences (Falus, 2004). In the research we combined various theories, models, methods and analytical tools within the patchwork approach of qualitative research (Denzin, Lincoln, 2011).

Our research was conducted using three main types of methods, namely inclusive research methods, focus group interviews and individual interviews, which we supplemented with various methodological techniques.

4.1. Inclusive research method

The theme of inclusive research runs throughout the whole patchwork, a person with physical disability participated actively in the research process. The inclusion of the person with physical disability allows the research to be having more personal meaning for the subjects, which in turn contributes to their experience of empowerment and bridging social distances. Within these groups a participating members contribute to the validity of the study, since they help form the research questions considering the special characteristics of the target group (Mercer, 2002). Continuous controlling is made possible by combining the view of external researchers with the local experiences of the “insiders” (van der Riet, Boettiger, 2009).

The person with physical disability was primely an insider expert in the research, participating actively in the whole research process, from creating the research questions to analysing the results.

We proved to increase the level of participation of all the interviewees within the process of the research. Subjects were able to participate in the first step of making an analysis with SWOT-analysis in the focus group interviews and with timeline methods in the individual interviews (Adriansen, 2012; Leigh, 2010).

4.2. Focus group interviews

The aim of the focus group interviews in the research is to map the perceived social aspects of the transition to adulthood of people with physical disabilities in point of view of the different possible concerned persons. According to the interpretive approach this may be revealed by the interpretation given by key persons (Goodley, 2011). As the various protagonists exchange information and acknowledge each other’s viewpoints, complex suggestions for solutions may evolve, in which the participative element is also determinant (Bloor, Frankland, Thomas, & Robson, 2001; van der Riet, Boettiger 2009).
New aspects of the topic may emerge in the conversations had by the groups, which can help in making the individual interviews (Vicsek, 2006). This is also happened in this research study.

A number of people with physical disabilities undergoing the transition to adulthood participated, with the same distribution in all groups. The groups comprised people with physical disabilities, parents, special needs educators, social workers, leaders of organisations associated with people with disabilities, politicians specialising in disability, the insider expert with physical disabilities, an assistant and a moderator, who acted as the leader of the research.

We accessed the interviewees by a snow-ball method, with mediators recruiting the participants (Bloor, Frankland, Thomas, & Robson, 2001).

In social science focus group interviews a minimum of three groups with the same combination is recommended (Vicsek, 2006). In this research we also have three groups with the same combination.

As a zenith of the focus group interviews the participants analyzed the Hungarian situation using SWOT analysis, with regard to the level independent living and community participation as specified in Article 19 of the UN Convention. We asked the respondents that they thought about the strengths and weaknesses from the viewpoint of the respective groups that they represent (e.g. special needs educator, parent). They analysed the opportunities and threats from the considering any external, social factors (Leigh, 2010).

We analysed the focus group interviews both with quantitative and qualitative methods. With the help of Atlas.ti 5.5 software we also examined the quantitative characteristics of the texts of the interviews (e.g. word frequency). The frequencies of the responses of the participants give quantitative information about their degree of dominance or any peripheral situation in the groups (Ehmann, 2002).

We analysed the texts primarily with a thematic method, arranging the different parts of the interview according to the appearing dimensions and blocks in the interview questions (Hüse, Kiss, 2008).

We classify the contents of the interviews in a deductive way, based on the system of viewpoints combining the resilience theoretical analysis matrix and the social constructionist approach of Runswick Cole and Goodley (Cárdenas, López, 2011, Runswick Cole, Goodley, 2013). New aspects also appeared emerging from the texts inductively (Szabolcs, 2001). Sometimes we cannot refer to only the inductive or deductive approach, as the conclusion can move from the individual or from the general to many directions depending on the previous knowledge and assumptions of the researcher (Sántha, 2011).

4.3. Individual semi-structured life world interviews

The aim of the individual interviews to is to gain insight into the lived experiences of the transition to adulthood and resilience of people with disabilities in connection with the attitude of their parents. We tried for identify junctions of the transition to adulthood and independent living, and supporting and restrictive factors in the transition to adulthood, highlighting the conditions created by society.

We conducted semi structural life world interviews (Kvale, 2005) with people between the ages of 25 and 40 who have had physical disabilities since childhood. We also conducted interviews with their parents. We mapped sixteen courses of life, as well as conducting thirty-two interviews with parents. Half the participants live in Budapest and the outskirts of the capital, and half of them live in the country.
We used expert sampling, we had formal criteria determined in advance. On the other hand we found the interviewees who lived in a closer world with snow-ball sampling (Plummer, 2013).

At the end of each interview we used a timeline method both with the adults with physical disabilities and their parents. A timeline is a horizontal line on which the participants were asked to summarize the supporting and restrictive key events they encountered in making the transition to adulthood and independent living in their lives. With this method we could illustrate visually the different steps of transition to adulthood and independent living, and the subjects were able to participate in the first step of making an analysis (Adriansen, 2012; Patterson, Markey, & Sommers, 2012).

We analysed the interviews with a thematic method, comparing the elements appearing in the interviews by collecting similarities and differences. We tried to create types according to the related elements which stood out from the interviews. We joined mosaic information regarding the social level of the subjects (Hüse, Kiss, 2008).

We used Atlas. ti 5.5 software both in the quantitative and qualitative analyses (Ehmann, 2002).

The interview analysis had several phases. In one part we applied the category system which created for the focus group interviews linking the factors of resilience with the texts of individual interviews in a deductive way.

However, elsewhere we took into consideration the new aspects derived from the texts, and we formulated the codes under the four main categories in an inductive way, where the qualitative analysis appeared next to the quantitative one, and a deep understanding emerged beside the frequencies of the codes (Szabolcs, 2001). We can also follow up abduction in the creation of the codes. We do not only start from the texts, since we had previous assumptions and we return continually to the codes (Sántha, 2011).

The main code system of the interviews is shown in the table below, which was created by the combination and slight modification of the models of Cárdenas and López and Runswick Cole and Goodley (Cárdenas, López, 2011; Runswick Cole, Goodley, 2013).

<table>
<thead>
<tr>
<th>Structural</th>
<th>Cultural</th>
<th>Relational</th>
<th>Individual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supporting</td>
<td>Restrictive</td>
<td>Supporting</td>
<td>Restrictive</td>
</tr>
<tr>
<td>system level resources, accessibility</td>
<td>attitude of society</td>
<td>family environment</td>
<td>power and control</td>
</tr>
<tr>
<td>law, policy, practice</td>
<td></td>
<td>educational environment</td>
<td>bodies and minds</td>
</tr>
<tr>
<td>workplace environment</td>
<td></td>
<td>friends, direct environment</td>
<td>identity</td>
</tr>
<tr>
<td></td>
<td>relations with professionals</td>
<td></td>
<td>cohesion</td>
</tr>
<tr>
<td></td>
<td>community participation</td>
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</tbody>
</table>

The attitude of the parents and its connection with the transition to adulthood of people with disabilities is a significant analytical factor. Based on the courses of life we tried to create an aggregate timeline and constitute types regarding parental socialization, transition to adulthood and resilience.
5. SUMMARY OF THE MAIN RESULTS

5.1. Answers to the research questions and assumptions

How does society delineate the social adulthood and independent living of people with physical disabilities?

According to the social aspects interviewees with physical disabilities experience predominantly restrictive factors in their lives. The social aspects are thematised mostly as of fortune factors in narratives between adults with physical disabilities and their parents: eventuality and fragmentation are common features in their lived experiences.

How do people with physical disabilities know their way around in the social frames? How are social adulthood and independent living realised in the course of their lives?

All the interviewees encounter restrictive factors and eventuality created by society, but to a different degree, and they respond to these in different ways. The parenting attitude significantly determines how people with physical disabilities face these barriers. These also have an influence on their transition to adulthood. The criteria of transition to adulthood are unreliable, but self-determination is an unquestionable part of adulthood. Detachment from parents is not definitely one of the criteria of adulthood. One way of succeeding in society occurs when adults with physical disabilities struggle against social barriers in a strong coalition with their parents. Instead of the myth of full independence we have to consider some level of dependence. Adult identity is often unstable in courses of lives.

How is the transition to adulthood supported? In what ways can this be restrictive?

We identified the supporting and restrictive factors in structural, cultural, relational and individual processes in the texts of the interviews and in the timelines. The supporting factors are dominant in the relational and individual processes, but relational processes emerge in both of them. Structural and cultural processes are mainly restrictive in the courses of the subjects’ lives. In relational processes the family, the environment of education and work, friends, leisure groups and communities may support the transition to adulthood if they do not consider the person with physical disability according to the dependent, passive role is allocated by society. In individual processes power and control may contribute to reaching adulthood as cohesion which is an imbalance between interest and responsibility also does. Identity also plays an important role in the individual processes. The elements of structural and cultural processes may sometimes support adulthood e.g. the use of telecommunications, the improvement of accessibility or increasing of acceptable behaviour. The listed agents of relational processes are restrictive if they consider the person with physical disability according to the dominant dependent passive role created by society. In the individual processes the low level of power and control, the lack of cohesion and the lack of acceptance and adult identity could be restrictive. These barriers, which are socially determined according to the subjects’ physical condition, could set back the dimension of bodies and minds. In structural processes the lack and eventuality of system level resources are mostly restrictive, in which the role of the fortune factor is dominant. In cultural processes the barriers are embodied in the attitude of society (Cárdenas, López, 2011; Runswick Cole, Goodley, 2013).
How do family socialization and parental attitudes contribute to people with physical disabilities attaining some level of social adulthood and independent living?

Family socialization is a determinant in how the parents give their child the possibility to confront restrictive factors and how much they identify with the role created for them by society. The parents struggle against the barriers or they confront the common social requirement and allow their child to experience the barriers alone. Resistance against barriers may be successful in both cases, but where the power is mainly in the hands of the parents, the level of self-determination is lower. However, where people with physical disabilities also face the barriers individually, the level of self-determination is higher and this leads the subject in the direction of independent living.

Assumptions:

1. Contrary to the requirements of UN Convention, people with physical disabilities encounter many social barriers regarding the transition to adulthood and independent living. For these people, Article 19 of the convention is only realised at a low practical level, external obstacles (threats) having more significance than internal weaknesses (SWOT analysis).

In the focus group interviews the participants emphasize the extraordinarily low level of implementation of Article 19 of the UN Convention. Many external threats are presented but the participants also detail more internal weaknesses, so any obvious swing of emphasis is not visible. The external threats eventuate the necessity of more internal resources that also have shortcomings according to the participants. They perceive primarily the low level of self-advocacy among internal weaknesses. Yet in the individual interviews, as opposed to the focus group interviews, we can conclude that the restrictive factors created by society have a predominantly greater emphasis than the individual barriers.

2. In the lives of people with physical disabilities transition to adulthood has no fluency, and they experience difficulty in overcoming social barriers created, so the period of post-adolescence may be extended, or they could remain in permanent post-adolescence. To move on from this socially determined post-adolescent status they need to develop strategies for building resilience.

According to the experiences described in the subjects’ life stories, the transition to adulthood is not fluent, and they have to encounter many barriers. Escaping from the role of a post-adolescent they definitely need to have resilience, but its dimensions appear in the individual processes. A person with disability can escape from the post-adolescent role, if he/she also faces these barriers alone to some degree.

3. The capacity of people with physical disabilities to acquire resilience and resistance to social barriers depends significantly on the attitude of the parents to their child, which may influence the dimensions of their social adulthood.

   3.1. If the parents treat the person with physical disabilities as a child, and the parents have an authoritarian attitude, the person’s level of resilience will be lower, resulting in a lower level of social adulthood, and, typically, their having a post-adolescent status.
3.2. If the parents treat the person with physical disabilities as an equal, and the parents have a "democratic" attitude, the person’s level of resilience will be higher, resulting in a higher level of social adulthood, and, typically, their having an autonomous adult role.

According to our interviews the only part of the assumption which was verified was that which concerns the transition to adulthood. If the parents treat the person with physical disabilities as a child, and the parents’ attitude is authoritarian, the role of post-adolescence is really more typical. Yet this does not correlate with the low level of resilience according to the complex definition, since this connection is only visible in the individual processes of resilience. Resistance to barriers could also be successful, if the parents consider the adult person with physical disability as a child and their attitude is authoritarian. In this case the main resources are the relations and adult role does not fully materialise. If the parents have a “democratic” attitude and treat the person with physical disability as an equal, the adult role is more typical, there is higher level of resilience, but beside the relational processes individual processes also become manifest. Contrary to the two previous assumptions a more differentiated picture of three distinct constellations stand out in connection with the attitude of parents, transition to adulthood and resilience. In the first type the parents roll away the barriers facing the adult person with physical disability, in resilience the supporting factors of relational processes are dominant in creating resilience, power is in the hands of the parents, and the person has a low level of adulthood and responsible self-determination. In the second type adults with physical disability are in strong coalition with their parents, so the supporting factors of relational processes play a greater role in overcoming barriers, but the parents treat their child as an equal, so the power relations are more symmetrical between them, and the level of adulthood is higher, which is manifested in self-determination. In the third type parents consciously try to free their child’s hands gradually, and the individual experiences and supporting factors also become important, and so the level of self-determination is the highest in these cases, and independent living skills also appear.

3.3. If the parents accept the status of their child with physical disabilities, the person’s level of resilience will be higher, resulting in a higher level of social adulthood.

There are differences in the subjects’ acceptance of the situation, and in the narratives two attitudes appear. Some parents are not constrained by realistic considerations of their child’s situation and are optimistic about finding the best solutions. Acceptance may contribute to more successful resistance but this does not mean that there is a higher level of adulthood, as in such cases it may be that the parents’ own efforts are determinant. In other cases the level of acceptance is lower, the parents’ narratives are more pessimistic and they are less likely to believe that coping with the barriers will be successful. In these cases there are lower levels of successful resistance and a lower level of adulthood too.

4. The local environment also has an influence on resilience, those interviewees residing in the capital or in its outskirts being likely to encounter fewer obstacles, with the result that internal, individual compensatory factors have a greater impact on resilience, and they resort to less external (family, environmental) support. Those interviewees living in the country are likely to encounter more obstacles, with the result that internal, individual factors are not sufficient, and external (family, environmental) supports carry more weight.
This assumption is not verified in this form based on the interviews, as both in the capital and in the country the relational compensatory factors have the most emphasis. Yet in the interviews made in the country the relational processes are thematized better and the structural and cultural processes are thematized less than in the capital. In the lived experiences of the interviewees social factors, whether supporting or restrictive, play less of a role. This may be due to the fact that the typical lifestyle of the capital or its outskirts requires more infrastructural facilities and means that people have to leave their comfort zones, while with the country lifestyle they can encounter fewer barriers in the more sheltered and more familiar environment primarily with assistance from others. In the capital even people with more severe physical disabilities have greater individual freedom of movement thanks to higher levels of accessibility, so compensatory factors derived from individual processes may carry weight. However, in the country, where the level is accessibility is lower, even people with less serious disability have to rely on others for help.

5. 2. Outlook, the possibility of practical use

In the course of the SWOT-analysis of focus group interviews we obtained a picture of the strengths and weaknesses of the key persons and the external opportunities and threats. From the results the possible solutions to practical problems became apparent.

The role of will-power and the lobbying activity of persons with physical disabilities feature in both the strengths and weaknesses. Although these could be strengths, when they are lacking or diminished the threats posed by the requirements and social roles mediated in the socialization process become dominant. For family and education it would be worth moving away from the provision of care that leads to passivity in the recipient. This is true in all care professions (special needs educator, social worker etc.), in that a person with physical disability may escape from the inferior, passive, cared-for role to an equal, active, independent role. In this regard, self-recognition and self-advocatory groups may aid the social participation of people with physical disabilities.

Ambition and the motivation of parents is basically a strength that would be of use in creating help groups where the aim is to find those limits which rather assert the side of weaknesses.

At special needs educators, besides the necessity of providing education and promoting a role of citizenship, they mentioned the importance of thinking in teams, although the lack of common language and the low level of inclusion of families show low effectiveness in this area. Interdisciplinary cooperation helps in the formation of the common language, dialogue and communication needed by all concerned to find effective solutions to the problems. Awareness of rights is also important in special needs education, so it is worth promoting this at a higher level, both in education and in social-policy.

Viewpoints as to the strengths and weaknesses of social workers are also often misleading, for example professional knowledge and uncertainty and inconsistency may be present at the same time. The key to improving this lies mainly in the communication that needs to be developed among professionals as well as between professionals and the people concerned.

As for the leaders of organizations, improved communication is also necessary, and professional consciousness has to be extended to the role of advocacy.

Despite their knowledge, attitude and legal background, policy representatives specializing in disability identify having a fragmented, flawed policy as a weakness. Hence,
they have to pay more attention to elaborated strategies and need to develop further cooperation with others.

The attitude of society is a relevant threat with its prejudices and allocation of social roles. We have to pay more attention to how we shape the approach of society, transferring the knowledge and sensitization that are also demands of the concerned persons.

Further demands include taking direct action to meet individual demands, such as making work-places accessible, making education marketable, involving concerned persons in planning, promoting cooperation between different parties as well as the preparation and equipping of civil organizations.

The strategies of the European Union may help by offering tenders to create resources.

The eventuality of fortune-factor may provide solutions in social policy. They have to resolve the fragmentation of the social service system, the paradox of law and practice with filling the holes. The lesson of the focus group interviews shows that for real change the communication and cooperation of key persons is needed.

With analysis of the individual courses of lives we may see how the concerned persons and their families live the eventuality of social environment. Families need a high level of flexibility to support their children’s transition to adulthood. Hence, coaching families is very important in order to determine the appropriate limits of care. In this expansion of psychological and mental hygiene possibilities, parent and peer groups and elaborated streaming of information may help.

Our results may also be of use to other groups with disabilities, and the wider accumulator lens of disability may aggregate common experiences.

Further research on the transition to adulthood and the resilience of people with disabilities may produce differentiated images (e.g. gender based or town-village comparisons), and this research may provide the basis of these images.

By trying this, the first such study using the inclusive research method to be employed in Hungary, we hope that other researchers may also wish to conduct research together with the concerned persons and in so doing further develop this method.

5.3. Summary

The main aim of the research was to examine how the social aspects of transition to adulthood are present in the lived experiences of people with physical disabilities, what supporting and restrictive factors they encounter, and how the attitudes of their parents affect both their transition to adulthood and their resilience.

Society imposes a dependent, passive role on people with physical disabilities (contrary to the independent, active role prescribed in international conventions). One way of success is through struggle but socialization agents do not equip them for this, resulting in a paradox situation. Society does not guarantee conditions for living in a comfortable, passive role, dependent on services, but they are not given enough opportunities (for example community based services) for independent living. According to the UN convention both the responsibility of society and the participation of people with disabilities have are stressed, but we have found shortcomings on both sides.

The socialization of citizenship in Hungary is seldom geared to activity and self-advocacy, and with regard to people with disabilities learned helplessness is more dominant.

If an adult with a physical disability is coerced to adopt a passive, dependent role in the process of socialization, and he/she identifies with this, then a relevant trap situation may arise. If a person with a disability acquires a fully valued adult role, then the key players in the
process of socialization, namely the family, have to deviate from the norms prescribed by society. However, struggle is also necessary, if those persons are socialized in a dependent, passive role by their parents, as effort is required to access various resources and services. To avoid this socially prescribed role the family needs flexibility as illustrated by the Olson family functioning model (Garai, Kovács, 2014). The role of provider parents, who offer their whole life to their child (Rozsos, Krémer 2009), and the passive disabled role of one who is dependent on his/her parents, which correlate with rigid family functioning are not effective in the period of transition to adulthood. Families have to move on from this if they would like to motivate their children to acquiring an autonomous, adult role.

Parents of people with physical disabilities may have different strategies for coping with this paradoxical situation. Three constellations have appeared in connection with parenting style, adulthood and resilience in the courses of the subjects' lives, in which the presence of power and control have proved to be factors of differentiation (McAdams, 1988; Runswick Cole, Goodley, 2013).

The use of a timeline was an appropriate method for illustrating the circumstances of resilience and the supporting and restrictive factors of transition into adulthood (Adriansen, 2012).

The most significant result of the aggregated timeline (figure 1) shows the expansion of the fortune-factor and the system level resources backing out gradually primely from the period of transition to adulthood. In more courses of lives we experienced the beginning of the transition to adulthood early primarily in its psychological aspect, then its reversal with the presence of barriers created by society.

Progressive focussing appeared during the research, which is typical in qualitative research (Szokolszky, 2004). This is manifest in a less explicit composition of hypotheses, as in our research our interpretations differed by the end of the process, specifying our previous assumptions. The combination of the ecological and social constructionist models of resilience is one of the results, causing a new theoretical frame to be constructed, which were shaping during the analysis of the interviews (Cárdenas, López, 2011; Runswick Cole, Goodley, 2013). The concept of adulthood is also changing continually, as we interpreted it with different dimensions. By the end of the research it became clear that in the mirrors of the interviews power and self-determination are the main element of the concept and the other dimensions build up to these.

The participation of 'insider expert' in the research was an instructive experiment. The shaping of their attitudes to research surfaced during the process in the relationship between the role of the researcher and that of the participant, and sometimes in a shift of equilibrium. The internal, "local" experiences of insider expert complemented the external, professional methodological knowledge of the leader of the research.

Additionally, the lived experiences of interviewees with disabilities and their parents and the interpretation of key persons participating in the focus group interviews established a uncertain social frame, in which assess to social resources and conditions depend on good fortune. Eventuality and fragmentation are common experiences detected in the accumulator lens (Waldschmidt, 2012) of people with physical disabilities, and they react to these in different ways. They may have to resort to different sources of resilience, which do not correlate definitely with having an autonomous, adult role.
1. figure – Aggregated timeline

Supporting

Support and struggle of the family

Care provided by the family, geared towards independent living

Struggle and the strength of the individual

Facing the challenges of life

Telecommunications

Community participation

Developments

Driving license

Relationships

Socialization and community in schools

Work

4  8  12  16  20  24  28  32  36  40

Deficiencies in the education

Lack of accessibility, difficulties in traffic

Lack of opportunities in the labour-market

Attitude, prejudice of society

Physical state

Lack of acceptance

Deficiencies in the social service system, the fortune-factor

Family events lived negatively

Comfort, lack of willpower

Uptight, protective attitude of the family

Restrictive
6. REFERENCES


Conference publications and conference presentations


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Studies published in journals


**Books, bookchapters**


**Other**