

LÍDIA BERSZÁN\*

## POSITIVE COPING AND RESILIENCE

### Questions and Conclusions Drawn From a Longitudinal Study

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In 2002–2004, during a research about families taking care of disabled children or adults, we created the criteria of coping successfully. Interpreting through this filter the resulting data and the responses a coping profile has outlined. Ten years later, we repeated the survey and found that in the interpretation of the data, the coping criteria from the first research was not sustainable. To better understand this phenomenon, we performed in-depth interviews and we added a CHIP (Coping Health Inventory For Parents) questionnaire that provides insight to coping behaviours used by parents. The results we obtained further highlighted our suspicion that the factor of successful coping from the first period of facing disabilities significantly changed through the years.

This phenomenon can be interpreted not only in terms of the life of individual families, but also shows the overlaps and differences between the meanings of the terms ‘coping’ and ‘resilience’, and the professional challenge brought by the supported resilience in the ‘overseeing’ of these families.

**Keywords:** coping, supported resilience, families with disabled members, resilience supporting model

**Positive Bewältigung und Widerstandskraft: Fragen und Schlussfolgerungen anhand einer Longitudinalstudie:** Während eines von 2002 bis 2004 durchgeführten Forschungsvorhabens mit Familien, die behinderte Kinder oder Erwachsene pflegen, haben wir die Kriterien der erfolgreichen Bewältigung erarbeitet. Anhand der Analyse der Daten und der Antworten mit diesem Filter zeichnete sich ein Bewältigungsprofil ab. Zehn Jahre später haben wir die Erhebung wiederholt und festgestellt, dass die Bewältigungskriterien aus dem ersten Vorhaben bei der Interpretation der Daten nicht beibehalten werden konnten. Um dieses Phänomen besser zu verstehen, haben wir Tiefeninterviews durchgeführt und außerdem einen CHIP-Fragebogen (Coping Health Inventory For Parents) eingesetzt, der Einblicke in die Bewältigungsverhaltensweisen von Eltern gewährt. Die Ergebnisse, die wir erhielten, haben unseren Verdacht bestätigt, dass sich der Faktor der erfolgreichen Bewältigung der ersten Zeit der Konfrontation mit Behinderungen im Laufe der Jahre signifikant verändert hat.

\* Lídia Berszán, Babes-Bolyai University Cluj Napoca, Faculty of Sociology and Social Work, Department of Sociology and Social Work in Hungarian, No 128, 21 Decembrie 1989 Bvd, RO-400604, Cluj-Napoca, Rumania; [berszan.lidia@gmail.com](mailto:berszan.lidia@gmail.com).

Das kann man nicht nur im Hinblick auf das Leben der einzelnen Familien interpretieren, sondern es zeigt auch die Überlappungen und Unterschiede zwischen der Bedeutung der Begriffe „Bewältigung“ (Coping) und „Widerstandskraft“ (Resilienz) sowie die fachliche Herausforderung, die die unterstützte Resilienz bei der Anleitung dieser Familien darstellt.

**Schlüsselbegriffe:** Bewältigung, Coping, unterstützte Widerstandskraft, unterstützte Resilienz, Familien mit einem behinderten Mitglied, Modell zur Unterstützung der Widerstandskraft, Modell zur Unterstützung der Resilienz.

## 1. Introduction

The 1989 change of regime in Romania opened many new chapters in the development of the social care system. The first decade was mostly about the mapping and acknowledgement of the lacks and urgent needs. A vastly unexplored area was the professional help of people with disabilities and their families. Instead of a highly paternalist view based primarily on the politics of silencing and hiding, the care system supporting people with disabilities and the attitude towards disability had to be based on a scientific approach, and a basis of an inclusive social view and professional cooperation.

Out of the many sociological theories aimed at the social understanding, research and conceptualisation of disability (MAY & RASKE, 2007; SIEBERS 2008; GOODLEY 2016), this present study is based on the interpretation paradigm of *functionalism and individual deficit* presented also by Goodley. The focus of the longitudinal research is the question: which are the supportive factors found in the individual, family and social care system that enable positive coping with disability as a status, and also, does the initial coping mean a functionality sustainable in the long term, can it be considered resilience? (GOODLEY 2016).

## 2. Longitudinal research on the situation of children/youth with disabilities in Romania

The primary task of our longitudinal research was to offer as much information as possible about families raising children and/or young people with disabilities, which serve as a basis to analysing their coping mechanisms with the new life situation caused by the disability.

The first research was conducted in 2002–2004. The sample consisted of 400 families from Transylvania, living in 108 settlements of 9 different counties. The age of the children/young people in these families was between 0 and 23 years.

The second research went on in 2012–2014. We assessed the interviewees of the first research again 10 years later. The age of the children/young people in these families was between 10 and 28 years. This second research included 100 families. Compared to the national average, severely and multiply disabled children/young

people are overrepresented in both samples since the effect of disability on families and the survey of community and social attitude towards them is primarily relevant in their cases.

The units of analysis were, in both queries, the families raising children with disabilities. The instrument of the research was a standardised quality of life questionnaire, developed and used by the Eötvös Loránd University's Institute of Sociology and Training Centre for assessing families of children with physical disabilities. We adapted and expanded this questionnaire in 2003, we used it in both the first and the second query. We followed the methodology suggested by Berg (LI-TSANG et al. 2001) in operationalising the data and in identifying the coping strategies. (For more information about coping strategies see: BERSZÁN 2007a; 2007b; 2007c; 2007d; 2009)

### 3. Conclusions of the first survey

One aim of the first research was to explore: what are the most powerful individual, family and social factors in relation to disability. According to the former results, one of the most determining factors is the *degree of disability* and the *domain of functioning*. Its effect can be traced not only in coping with the current situation (kindergarten, school-capability, educational type, aid eligibility), but also, in anticipating the future opportunities: the more cumulative and the more severe the child's disability, the more negative the respondent parent's vision of the future.

The settlement type also proved to be crucial in this research, both in quantity and in quality: from the county towns to the villages, the number and repertoire of options lessen, the truly integrated education supported by professionals is barely known, the concept of a 'parental group' is completely unknown in villages. Yet in many cases, the order breaks down, smaller towns get behind villages, problems get less attention: these do not receive neither the better supplies of the county towns nor the attention towards each other due to the closed nature of the villages. The deficiencies of the supply system seem to be partially offset by the support of the relationship system.

The effect of the *material background*, the *available supplies* is multidirectional. The parents' education and occupational status becomes effective only to the extent of better access to opportunities: these facilitate better orientation in the complicated procedure of obtaining assistance, development and educational opportunities. The majority of the families in the sample turned out to be in poor material conditions, although the unemployment rate was not higher than in the average population. In the case of the very poor families, a significant part of the family's income (more than half) comes from the sum received for childcare. However, in families in which the mother is required to stay at home, this causes the loss of an income, and with the extra cost of the development and the special diet, a material setback can be observed. The families with a medium and good material situation become poorer, the extremely poor get a modest income, but this is barely enough for survival.

The parents' main *resources* in coping with disability are family and faith. The negative effects of the environment: prejudice, rejection against disabled children and young people, all weaken these resources.

Only a small number of families caring for an adult disabled member made it to the first survey. In spite of this, it is evident from the analyses that their situation is increasingly difficult. When a young disabled person finishes their programme in schools and professional studies, their opportunities decrease significantly. When answering the questionnaire, several respondents described the dynamic of the process of facing disability as something that can be defined as a grieving process: from the *first coping to recovering again and again* after the difficult periods through the years. The life period considered or anticipated to be the most difficult by the parents is when their health would decay, their material and placement possibilities become limited, because they would reach the retirement age.

#### 4. The motivation behind the second survey

One of the strongest arguments for continuing the research and repeating the survey was the families, the parents' opinion: they believed that when their children would reach adolescence and adulthood, their parental coping skills would stand the real trial, but also would the supportive system.

On the other hand, the last decade's changes in social politics about the protection and inclusion of people with disabilities have reinforced the motivation to evaluate efficiency from the point of view of those affected. Hence, the primary aim of the query was to find out whether the rights provided by the law can be deemed as actual opportunities. Could everything promised by the regulations, described by the motto: '*equal opportunities for the disabled – towards a discrimination-free society*'<sup>1</sup> (*Strategia națională pentru protecția, integrarea și incluziunea socială a persoanelor cu handicap în perioada 2006-2013*, our trans., 4) be sensed? How do these affect the everyday life of families raising disabled children/young people?

#### 5. Changes in the support system in the period between the two researches

An important milestone in the decade between 2002 and 2012 was the founding of the National Authority for People with Disabilities (ANPH) in 2003, which was established to unite all the institutions active in this area, having assumed responsibility for the compliance of rights of all Romanian citizens with disabilities.

The 448/2006 Law (*Lege Nr. 448/2006 din 6 decembrie 2006 Republicată, privind protecția și promovarea drepturilor persoanelor cu handicap*) offered a new approach and a new understanding of disability. The core of the new interpretation is approaching disability not from, or not mainly from the regard of health status, but from the point of view of 'functional status', as suggested by the WHO, i.e. the skills

<sup>1</sup> Original text: 'O societate fără bariere pentru persoanele cu dizabilități'

required to conduct everyday activities, and from the dimension of rehabilitation, and social inclusion measures.

This same law contains the principles of the protection of the rights of people with disabilities, with a special attention to the respect for fundamental human rights, to social solidarity and social responsibility, to strengthening protection against neglect and abuse, and to equalising opportunities.

Another relevant local programme in disability care is the *Strategia națională pentru protecția, integrarea și incluziunea socială a persoanelor cu handicap în perioada 2006-2013* [National Strategy for social protection of disabled people, social integration and inclusion from 2006–2013]. The document is based on the following principles: society considers people living with disability, who are able to control their lives, active citizens; the government offers outstanding support and protection to the families that have disabled members, and it considers helping people with disability to integrate in the labour market as a priority.

## **6. Statistical and research data about the situation of children with disabilities in Romania**

In this topic, it is quite common that the data of the National Authority for People with Disabilities, the data of the Romanian Statistical Office and the research data do not match, moreover, the results provided by them are contradictory. These differences and the contradictions partially complete the overview of the situation of people with disabilities, partially contribute to a still existing strategy of ‘concealment’ or ‘embellishing reality’, which is the heritage of the communist era.

According to the 2012 data provided by the National Authority for People with Disabilities, there are 60 890 registered children with disabilities. An OECD research from 2007 keeps count of four times this amount of disabled underage children. If we consider these data as complementary to each other, we need to keep count of the fact that the one fourth of the disabled children of Romania are registered and they receive some kind of attendance. The rest, however, do not belong to the benefit system, they do not receive neither development nor support (for further information see: *Education Policies for Students at Risk and those with Disabilities in South Eastern Europe* 2006). According to the ANPH’s data, the vast majority (99.07%) live and are raised in their families or foster families.

## **7. A comparison of the results of the two surveys**

In the short presentation of the research sample we have already mentioned that in our sample, severely and multiply disabled children/young people are overrepresented. Examining the national data of the ANPH, we see that in the last 10 years there had been a strong shift in the matter of proportions from the ‘severe’ category to ‘profound’.

*Table 1*  
Classification in degrees of disability

<i>Severity of the disability</i>	<i>National data in 2002 (%)</i>	<i>National data in 2012 (%)</i>	<i>Specimen data (%)</i>
<i>Severe (gr. I.)</i>	47.32	33.7	59.5
<i>Profound (gr. II.)</i>	26.05	53.7	27.8
<i>Moderate (III.)</i>	26.63	11.52	7.8
<i>Mild (0)</i>	–	0.92	1.3

Source: ANPH's (National Authority for People with Disabilities) national database, <http://anpd.gov.ro/web/transparenta/statistici/trimestriale/2012>.

This shift might have two explanations: the evaluating commission of experts has experienced such an intensive improvement in the situation of children/young people with disabilities that it is strongly remarked in the national statistics. The other possible explanation is that based on some consideration, the classification criteria have drastically changed. According to the respondent parents, this latter one seems to be more probable. The parents had to fight vigorously not to lose the modest but often indispensable services ensured by being classified as 'severe': being a personal caretaker for the disabled child, and receiving travel and management discounts. In the majority (64.7%) of the families, a parent, usually the mother becomes the personal caretaker of the child; if she loses this status, there is a slim chance she might find a job after several years of being off the labour market. Being classified as 'profound' has significantly less material and other privileges. It seems that the seemingly positive changes in the national statistical data have been influenced by economical and savings aspects.

We gain insight into the changes in the educational opportunities from the following table.

*Table 2*  
Institutes they attend

<i>Type of institute</i>	<i>First research: 2002–2004 %</i>	<i>Second research: 2012 %</i>
<i>Kindergarten</i>	14.7	0
<i>School /vocational school</i>	36.8	40
<i>Employment day-care centre</i>	14.7	24.5
<i>Stays at home</i>	31	35.5

Kindergarten-age children from the first data collection have gone to school/vocational school or employment day-care centres. The rate of those staying at home or not belonging anywhere has slightly increased, and this growth is a cause for concern,

because the 2006–2013 Strategy placed the emphasis on the upkeep of the after-school age development and employment. The 448/2006 Law (*Lege Nr. 448/2006 din 6 decembrie 2006 Republicată, privind protecția și promovarea drepturilor persoanelor cu handicap*) and the corresponding Application Methodology emphasises the deletion of the terms ‘impossible to form’ and ‘impossible to educate’ from the assessment and enrolment procedures, and it introduces the outlining of individual development and guidance plans for each child with disability. This individual development guidance does not only have to point out the facilities that need enhancing, and the tasks that serve this, but also the geographically closest institute that can provide this. Parents of children not belonging anywhere had the following comments about their experiences:

*‘They have their development plans and they keep threatening us that if we do not go somewhere we will lose our subsidy but no-one tells me how I should transport my 90-kilogramme son with Down syndrome daily from the village where we live to the nearest institute that is 24km away. I myself can barely walk or get on the bus or get off the bus, we do not have a car, and neither the minibus driver accepts our travel discount.’*

*‘I will take him to an employment day-care centre, when he needs some normal job. He has studied furniture polishing, and he could do it, but colouring books and watching TV, well, he can do this at home. I would take him to physical education and speech therapy, but they won’t accept him because he is over 16 years old.’*

The survey applied a scale from 1 to 5 about the acceptance of children with disability by their environment, in which 5 meant acceptance, and 1 meant rejection.

*Table 3*  
Assessing the environment’s attitude:

<i>Assessment of acceptance–rejection</i>	<i>First research: 2002–2004 (average)</i>	<i>Second research: 2012 (average)</i>
<i>Relatives</i>	4.09	4.16
<i>Neighbours</i>	3.85	4.22
<i>Peers, children of the same age, young people</i>	3.16	3.47
<i>Passers-by, people in general</i>	3.14	2.56

Concerning the attitude of relatives, neighbours and peers, a slight improvement can be observed. However, the measure of acceptance has decreased in passers-by. In the majority of the disabilities, the difference, the otherness becomes more visible and more obvious with age, so prejudice and rejection prevails.

A parent’s response sums up the problem accurately:

*‘As far as I can see, every miracle lasts for three days, one can get used to anything. When my son was little and the relatives and the neighbourhood found out that*

*something wasn't right with him, many were curious. People came over with some excuse, but I knew they only wanted to see what that 'handicapat' [disabled] child looked like. Then, gradually, they got used to it, the family too, just as the neighbourhood and the children in our street. Today everyone says hi to us when I take him out in the pram. One must not always go after what people are saying. But sometimes people on the bus say: You should get that big boy out of the pram, why the struggle?!'*

In coping with disability, the family's resources are essential, and also, whether the parents and those closest are supportive or not. When asking about the resources, *family* and *faith* are still on the top of the list, both in the first research and in the second.

*Table 4*  
Who do you turn to with trust, when you need understanding or help?

<i>Understanding, help</i>	<i>First research: 2002–2004 %</i>	<i>Second research: 2012 %</i>
<i>Family members: husband, wife, healthy child</i>	66	60
<i>Grandparents, relatives</i>	58	42
<i>Friends</i>	39	23
<i>Parents in a similar situation (who also have a child with disability)</i>	22	16
<i>Experts (doctor, social worker, psychologist, etc.)</i>	51	24
<i>Foundation, organisation</i>	34	7

To us, the assessment of experts, foundations and organisations is relevant and also distressing, since both show a drastic diminution. This overview is completed by the inquiry about macro-level relationships.

*Table 5*  
On a scale from 1 to 10, how would you grade the following  
in their approach to people with disabilities?

	<i>First research: 2002–2004 (average)</i>	<i>Second research: 2012 (average)</i>
<i>Media, public opinion</i>	4.45	3.05
<i>Healthcare, hospital staff</i>	6.50	4.78
<i>Church</i>	7.53	7.02
<i>The Ministry responsible for people with disabilities</i>	4.71	5.41

With the exception of the Ministry responsible for people with disabilities, every value has decreased, but the Church still leads the list. The comments on the responses also partially give an explanation on the increasing grade of the Ministry:

*‘The Ministry doesn’t mean anything to me; I am thinking about those people that I talk to when I need to arrange my child’s papers. Over the years, I found out who is humane, and I went to them. I would give those people a 10, but there are also insensitive, materialistic people at these places too, and up there, in the higher ranks, many look only after their own gain, they don’t really care about us.’*

When we asked straightforwardly, what the things the families of children/young people with disabilities miss the most, we received many generalising answers, like ‘many things’, ‘health’, ‘so that the child would heal’. The following table sums up the more concrete answers.

*Table 6*  
 What are the things, which are the services that you miss the most, that the family would need the most in regard of their way of life?

<i>Missing services</i>	<i>First research: 2002–2004 %</i>	<i>Second research: 2012 %</i>
<i>Recreation opportunities, camps</i>	58	35
<i>Accessibility in public transportation</i>	39	28
<i>Temporary placement options</i>	24	24
<i>Other: advice on sensitive issues</i>	–	21
<i>Other: development, maintaining the level after the age of 18</i>	–	34
<i>Other: employment after school age</i>	–	39

Recreation options, camps mainly refer to camps for children with disabilities. The former and accessibility show slightly better results, but they are still on the list of deficits. There is an unchanged claim for temporary placement options. Three other items, which have partially been present, have made it to the list: development and employment, which point directly at the narrowing of options for education with age. Regarding the need for guidance, some of them specify the sensitive issues: *teenage problems, discipline, sexuality, relationships, aggression, self-aggression.*

About the vision of the future, we asked the parents to express in percent: what odds do they see for their child to learn a profession and find a job.

Table 7  
Assessing the visions of the future: learning a profession, job opportunity

<i>Vision of the future</i>	<i>First research: 2002–2004 (average)</i>	<i>Second research: 2012 (average)</i>
<i>Opportunity to learn a profession</i>	32	26,4
<i>Job opportunity</i>	32,24	3,29

Both values have decreased, but the almost 10 years between the two surveys have basically razed the respondents' hopes about the real chances of making money out of paid jobs, and not only from support. This question points out most obviously that the rights prescribed by the law do not automatically mean opportunities too.

The last question refers to the respondents' experience and opinion about the changes in disability care in Romania in the last 10 years. They had four answer options: 'negative', 'positive', 'unchanged', and 'I cannot decide'.

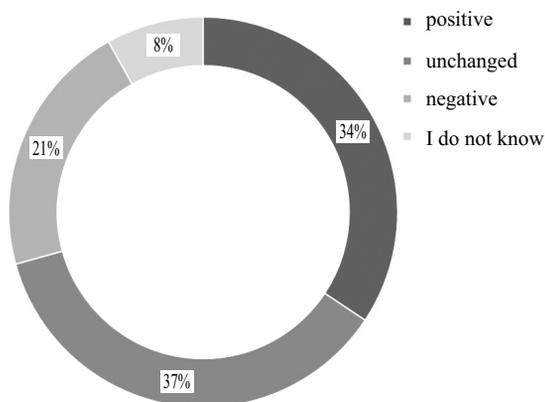


Figure 1  
Opinions about the changes in the support system

If we consider 'unchanged' as being negative, then along with the responses about the vision of the future, this also expresses dissatisfaction, disappointment with the support system.

## 8. Resilient parental coping with the child's/young person's disability

Definitions of resilience always emphasise the interactive nature of this particularity. When researching the opportunities of supporting resilience in case of disability, it is evident that we first need to assess the presence or lack of the support of the family and the environment.

The unity and a common coping, which, just like individual resilience, is defined by various factors inside and outside the family, is called *family resilience* by WALSH (2009). The family's belief system, organisational patterns, as well as communication and problem solving abilities are considered internal factors.

Belief system, in this context, does not only refer to the existence or lack of belief in God, but also, to all the pursuits and convictions that give meaning to disability. From the point of view of the family's resilience it is essential whether they have a positive or at least acceptable belief about the great *Why?*, and whether they can interpret it as a challenge, a mission. Another cardinal issue is whether this belief is common and whether it belongs to the entire family or not. If it is considered a common mission, a joint challenge, even a severe disability can become a common, unifying force. It is easier to keep the hope alive together; it is easier to think about the future. The faith shared and exercised in unity, the confidence in a transcendental force might give meaning and aim beyond the problems of this life. It provides dignity and endurance, and every spiritual act of faith has an obviously protective effect on maintaining mental health: prayer, holidays, religious family and community experiences.

The organisational patterns of the family are primarily defined by the flexibility of family roles and the quality of the ties. Disability repeatedly disrupts the balance many times. Increased flexibility is required for the family members to be able to function in a compensatory manner, and keep on rediscovering the balance. A mutual support and commitment, an adoption and respect of each other's limitations and a particular way of response is a learning process that can help maintaining resilience.

The congruence and clarity of family communication, the open expression of feelings (sadness-joy, anger-gratitude, fear-confidence, etc.) are determinative in the quality of family life. The emotional burden is significant with the presence of disability, and the family members' emotions can expand on a large scale. A supportive familial atmosphere does not mean repressing negative emotions, but assuming the responsibility for one's behaviour, and the endeavour for positive interactions. Opening up the valve of negative emotions can be part of this openness, as long as it does not burden the family atmosphere, and it does not become unilateral: a family member keeps on complaining, and the others have to be strong. The practice of humour, forgiveness, and enforcing, recognising, positive feedback is the essence of good family communication. When present, problem solving, the pursuit for creative solutions, and paying attention to exploring one's options become easier. (WALSH 2009)

## **9. Assessment of coping attitudes**

Before analysing the coping indicators and resilience found in our research, we considered it important to assess the similar researches about the topic of disability and resilience.

In a 2002 research, Weiss found that the mothers of disabled, autistic children are more resistant regarding depression, anxiety, and depersonalisation indicators; they have fewer somatic complaints, and they did not show any significant difference about the assessment of their parenting effectiveness from the normal average (as cited in IONESCU 2013).

HASTINGS and colleagues (2006) registered the Parental Stress Index of mothers raising children with disabilities (75 people). They had found that two-third reached a level above clinical threshold, they repeated the survey two years later, and the values remained stable (as cited in IONESCU 2013).

CONNOLLY-NOVAK (2007) experienced the following while assessing adaptation strategies (F-COPEs, 2001-Family Crisis Oriented Personal Evolution Scales): there are five different attitudes in confronting stress situations caused by disability: 1. one seeks community support (68%), one always speaks about distress and bad events to a family member; 2. one frames stressful events positively in order not to be discouraged and to digest them easier; 3. faith in God becomes more intense: one participates in worshipping more often; one looks for spiritual support and experience; 4. the entire family sets off to look for help, a solution in case something is not going well (in 93% of the cases, from people in the same situation, 80% from community programmes, 56% from experts); 5. avoidance, expectant attitude, passivity: watching TV, waiting for bad things to pass, waiting for things to work out (this also means not panicking) (as cited in IONESCU 2013).

PASTER and colleagues (2009) compared the coping strategies of parents raising a child with disability and parents with children that develop typically. Based on their results, they concluded the parents of children with disability used search for social support in a significantly higher rate, avoiding escape and positive revaluation was more characteristic to them. People with social support showed less signs of stress and depression, and it helped them having a plan for the future about developing the child and helping their accommodation.

KERSH and colleagues (2006) researched the quality of spousal relationships and factors influencing resilience in parents raising a disabled child, and also the mutual effect of these factors. They found that the correlation between marital satisfaction and parental efficiency was different in the case of fathers and mothers. In the case of mothers, the husband's support in raising the child with disability evidently defined their satisfaction with their spousal relationship. In the case of fathers, the feeling of parental efficiency and the complacency with their marriage did not show a significant correlation. They were more likely to define the quality of their marriage based on the time spent together, the social roles experienced together. Many noted that they became more resilient in their entire personality, in every aspect of their life: they paid more attention to their relationships, they started looking for the meaning of life, they went through a spiritual development, they raised the question of God, and they defined their life as a 'long and often painful, but positive development process' (KERSH et al. 2006, 884).

**10. Resilience assessment of our own sample**

At the second query, besides the life quality, life opportunity questionnaire we used a parental coping questionnaire. This survey was undertaken by 3 parents. The coping behaviour was surveyed by a CHIP (Coping Health Inventory For Parents; in McCUBBIN et al. 2007) questionnaire, which was created for parents of children with chronic or severe health problems or disability, and it asks about possible coping attitudes. The parents grade the 46 statements from the list from 0 to 4 (not helpful at all, minimal help, medium help, very helpful).

Factor analysis differentiates four subscales:

- I. Maintaining family unity, cooperation, and a positive assessment of the situation. The sum of points in the case of mothers coping positively is higher than 40.
- II. The presence of social support: family and social support relationships that sometimes help relieving parents of burdens. The sum of points in the case of mothers coping positively is higher than 28.
- III. Understanding and helping the situation of the family member with disability through consulting doctors, experts and other parents. The sum of points in the case of mothers coping positively is higher than 15.
- IV. Caring for myself, maintaining my own health, taking a breather every now and then, relaxing, and recharging. The sum of points in the case of mothers coping positively is higher than 23.

*Table 8*  
The parents' coping subscales

<i>Name of the subscale</i>	<i>Comparison average</i>
<i>I. Maintaining family unity</i>	> 40
<i>II. Social support</i>	> 28
<i>III. Understanding and helping the family member with disability</i>	> 15
<i>IV. Caring for myself, maintaining my own health</i>	> 23

These subscales are nuanced by the following: a) the child's age; b) is there a husband, and is he supportive with the mother in the family?; c) the quality of the relationship with the institute the child belongs to; d) faith in God. The older the child with disability is, the more important the family's positive coping skill will be.

In our own resilience research, the 37 respondents are all mothers. Every respondent has a child with disability over 10 years of age, and all of them belong to the 'severe' category of disability. There is a strong correlation between the points obtained by them at the subscales (Pearson Correlation = 0.000 – 0.002). We synthesised the results obtained in the following table:

*Table 9*  
 Characteristics of the successfully coping in regard to the resilience criteria

<i>Resilience criteria</i>	<i>Families</i>						
	<i>F. 1.</i>	<i>F. 2.</i>	<i>F. 3.</i>	<i>F. 4.</i>	<i>F. 5.</i>	<i>F. 6.</i>	<i>F. 7.</i>
<i>I / 40</i>	48	43	41	44	40	47	43
<i>II / 28</i>	40	50	44	38	44	38	40
<i>III / 15</i>	24	23	18	20	21	22	16
<i>IV / 23</i>	26	28	24	23	25	23	23
<i>The age of the child with disability</i>	23 y/o	18 y/o	38 y/o	43 y/o	31 y/o	24 y/o	18 y/o
<i>Is there a husband, and is he supportive?</i>	+	0	+	+	-/+	+	+
<i>The quality of the relationship with the institute</i>	+	+/-	+	+	+	+	+
<i>Faith in God</i>	+	+	+	-	+	+	+
<i>Total:</i>	112	116	103	102	105	107	99

According to the criteria of the aforementioned subscales, 7 people out of the 37 respondents proved to be resilient in the long run in coping with disability. In their case, the value of every subscale reaches or goes over the comparison average provided by the coping scale. Each of them has a child with disability over 18 years of age. In one of the 7 families the father passed away, and in one of the families the father's attitude is not evidently supportive. Each mother considers the relationship with the child's current institute positive (daytime employment centre, protected workshop, residential home). A deep interview was conducted with these parents, and it turned out that they had proved to be successfully coping according to the queries 10 years before, too.

Based on these interviews, we have found two accentual facilities: 1. There is institutional care for adults with disabilities in the families' residential area; 2. the mothers realised in time that they also need to look after themselves, because it is also important for the family member with disability that they do not sacrifice themselves, their health and important connections completely. In the deep interview they concluded without exception: one can sacrifice neither the marriage nor the good relationship with the healthy child/children, nor their own health and spiritual integrity on 'the altar of disability'. *'Less is often more'*, summarises a mother wisely. *'The child's disability cannot fill out and dominate everything. It is for their own good, if the father and the sibling does not flee because of the atmosphere'*. While in the coping with disability it was obvious that the successful ones would not send their child with disability to a boarding institute, in case of the long-term resilience, it

seems that the ones that do not plan on solving the question of the future in the family but they have found an opportunity and they can accept the boarding institute as a place of residence for their disabled child, can also be successful.

The ‘coping strategy’ that had started to outline during the first research, became more emphasised during the interviews: coping consists of the initial coping and of recovering again and again after the tough periods over the years. The families that proved to be resilient also went through several crucial periods, every now and then they lost balance, but they managed to recover repeatedly.

## **11. Instead of conclusions**

The present study was looking for answers, through processing the partial results of a longitudinal research, to the question: what kind of effect do the changes in the service system have on the daily life and coping capability of families raising and caring for children/young people with disabilities. The size of our research sample does not entitle us to comprehensive conclusions, but they definitely outline a direction, they mark a tendency. These families either do not sense the development in the service system in the last 10 years, or they experience it as the narrowing of legitimacies and education, development, and job opportunities. Their vision of the future is mostly negative. The attitude of the public opinion, the media, and the healthcare system towards them is mainly sensed as rejection, experts and advocacy organisations are not perceived as cardinal helpers and trustees. On the other hand, the relationship with the family, the relatives and friends, faith and the micro-environment remain the main support and resource. The assessment of the Ministry responsible for people with disabilities, the necessity for advising about the lacking services show that they do not reject professional help completely. However, the possibility of an institute that would take over some of the daily employment tasks of the family member with disability is most definitely a supportive factor.

There is still an existing distance between the provisions for inclusion and normalisation, the slogans about these provisions, and the everyday life of children/young people with disability and their families. The distance between the practice of law of the macro-system and the opportunities visible in the individual fates are still to be bridged.

## **12. Supportive model of resilience and community tasks**

About the correlation between coping and resilience it can be stated that a crucial step after the confrontation with the fact of disability is acceptance and positive coping. But whether a parent/a family can maintain this positive coping in the long run, and whether the initial acceptance would become individual, family resilience – these have many aspects in social politics. In places where there is an employment centre or daytime care for adults with disabilities, where there is a chance of moving to resident homes when the parents, due to their age and health, would struggle with facing

the challenges, and where there is a chance of a ‘respiro’, there is a smaller threat of a breakdown or exhaustion. Besides these – as the coping questionnaires, and more so, the deep interviews show –, only understanding and accepting that sometimes ‘less is often more’ can help: in the long term, they could support their disabled child if they gave up the claim to sacrifice everything for them, and they paid more attention to maintaining their physical and spiritual health.

As a summary, we have a question instead of a moral: which are those social and familial or individual factors that would be recommended to work out an efficient supporting model for resilience? It is crucial that the helping expert knows the support system and the relevant regulations well, and also, the establishment of a hierarchy of tasks, action plan, specific steps, long-term accompaniment and availability. If the casework is the priority, then a 3D-overview would be necessary: one must plan based on the current family life cycle, the individual life cycle of the family member with disability, and the specific criteria of the type of disability. If we approach from the community support, then the tasks of the social pedagogue and/or the social worker could be teaching and practising an accepting attitude and inclusive approach.

The majority of the researchers and the edifications of the present research agree on the fact that there is no universal recipe, but some recommendations can be outlined: first of all, looking for protective factors in the concrete situation of the individual and the family, and after that, creating the balance between the community provocation and support.

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