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The Families of Special Needs Children from the Perspective of Vulnerability

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☞ Difficult life circumstances can make anyone vulnerable. For example, families of children with special needs are at risk, as are families facing other stressful circumstances, such as poverty or parental mental illness. This article builds on previous action research by Plavčak (2020) and introduces a new research problem. We conducted a qualitative analysis of action diary data to answer two new research questions: 1) In what forms did vulnerability appear in students' families, and 2) What approaches did professionals use to reduce perceived vulnerability? Our findings suggest that families of children with special needs should be approached with sensitivity, flexibility, and balanced interventions. It is important to understand families in the context of their lives, including the emotional stages of caring for a child with special needs and other difficult circumstances they may face. Interventions should be tailored to the specific needs of families and developed collaboratively with them.

Keywords: vulnerability reduction approaches, families with children with special needs, vulnerability

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Družine z otroki s posebnimi potrebami z vidika ranljivosti

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≈ Ranljivost se lahko razvije pri vsakem posamezniku zaradi težkih življenjskih okoliščin. Dejavniki tveganja za nastanek ranljivosti so tako v družinah z otroki s posebnimi potrebami kot tudi v družinah z drugimi stresnimi razmerami, kot so revščina ali duševne bolezni staršev. V članku je predstavljen nov raziskovalni problem, ki se nanaša na že izvedeno akcijsko raziskavo (Plavčak, 2020). S kvalitativno analizo podatkov iz akcijskega dnevnika smo odgovorili na novi dve raziskovalni vprašanji: (1) v katerih oblikah se je pri družinah z učenci s posebnimi potrebami pojavljala ranljivost in (2) katere pristope smo strokovni delavci uporabili, da bi zmanjšali zaznano ranljivost. Rezultati kažejo, da je treba do družin z otroki s posebnimi potrebami pristopiti z občutkom, prožnostjo in uravnoteženostjo intervencij. Družine je treba razumeti v njihovem življenjskem kontekstu, upošteva je faze čustvovanja pri skrbi za otroka s posebnimi potrebami in morebitne druge težke okoliščine. Intervencije naj bodo usmerjene v projekte pomoči, ki izhajajo iz konkretnih potreb družin, in naj nastajajo v sodelovanju z njimi.

Ključne besede: pristopi za zmanjšanje ranljivosti, družine z otroki s posebnimi potrebami, ranljivost

Introduction

The literature review examines the concept of vulnerability, explores various forms of it in families with children with special needs (SN), and discusses practitioner approaches to addressing vulnerability. The introduction concludes by presenting the research problem and associated research questions.

Literature overview

The concept of vulnerability

Feetham and Deatrck (2002) note that the definition of vulnerability is shaped by factors such as family, culture, and society and that populations at risk can include minorities, immigrants, refugees, women, and families living in poverty. Knitzer and Lefkowitz (2006) add that vulnerability is caused by a combination of risk factors that may be present in the child, in the family, or in the environment. One example of a risk factor could be a life circumstance such as single parenthood or teenage parenting or an individual's lack of employment or education. There is also a risk of vulnerability when parents are unable to provide adequately for their children for a variety of reasons (e.g., depression, inconsistent parenting, violence, and substance abuse). Teixeira de Melo and Alarcão (2011) agree that any difficult circumstance can be a risk factor for vulnerability.

According to Feetham and Deatrck (2002), vulnerability refers to the increased likelihood that an individual will experience negative psychological, physical, social, or developmental outcomes when exposed to the aforementioned risk factors.

At certain points in life, everyone is vulnerable when dealing with stressful circumstances, but the previously described life situations and/or characteristics of the individual's biopsychosocial state indicate less opportunity and strength for positive outcomes, especially if the individual experiences more of them at the same time.

Families with SN children are some of the many families who face several challenges (Teixeira de Melo and Alarcão, 2011), also referred to as stresses (Madsen, 2007) or problems (Walsh, 2016). Taking care of SN children has changed their lives, as they have had to adapt many of their daily tasks to the new situation. Other families also face life-changing events, stresses, and problems.

Some researchers have questioned the term 'vulnerability', arguing that it may be overly broad and neglect important individual differences among families and the rights of the child, as suggested by Bauer and Wiezorek (2016). Specifically, it emphasises weaknesses, discomfort, and possible negative outcomes

while leaving in the background possible sources of strength in the family, the environment, or at the systemic level.

Therefore, each family needs to be understood and approached in an individualised way.

Some possible forms of vulnerability experienced by families with SN children

Some of the specificities of these families are due to the special needs of the child, such as emotional phases, but there may be other circumstances that contribute to vulnerability as well, such as mental health problems in the parents or placement in a foster family.

Trtnik (2007) summarises the emotional stages that families with SN children typically experience: 1) shock, 2) denial, 3) a crisis of values during which parents process feelings of guilt and fear while seeking as much information as possible to understand their child's special needs, and 4) a crisis period during which parents focus on therapies and corrections for the child and learn about the child's actual capabilities. This period may also include the institutionalisation of the SN child, leading to separation from the parents. Gantar (2009) conducted non-standardised interviews with eleven parents (ten mothers and one father) of SN children enrolled in a mainstream primary school. She also analysed data from the Decision on Additional Professional Assistance for the SN Child, which in Slovenia includes a definition of the child's deficits, obstacles, or disorders, as well as the number and type of additional professional help and adjustments to teaching. After qualitatively analysing all of this data, she found that parents had bad experiences with the accuracy and commitment of practitioners, but they continued to look for ways to improve their child's condition. They were willing to sacrifice their free time to ensure their child could finish their education, among other things. Sagadin (2013) found that parents who have children with behavioural problems experience additional stress.

Lochs (2016) conducted a study in Austria and Germany on a sample of parents with mental illness. The sample consisted of parents with children under six years of age (not defined as SN children) at the time of mental health problems. She was interested in how this affected their children. The results showed that parents were unable to provide their children with sufficient educational guidelines, guidance, and emotional support from an early age, which led to problems in their children's social and mental development and, in some cases, alcohol dependence. The article addresses the social aspects (organisational, professional, personal, familial, legal, political, and sociopolitical factors) of the emergence of children's problems. Regardless of the origin of the

problems, these families require appropriate professional support for their unique circumstances. 'This need for supported parenting applies to all parents interested in their children's wellbeing, even if the children are in out-of-home care' (Lochs, 2016, p. 101). The need for professional parenting support was perceived in all phases of the child's development, both in early childhood and in the growing-up period, namely in understanding the child's development process and dealing with their own fear of loss.

Lena (2016) analysed families with multiple risk factors, such as an absent father or a two-track upbringing, which made them vulnerable. The results showed that these families often functioned as closed systems, with inconsistent parenting and aggressive behaviour in the children. Aid institutions intervened to support the process, but families were not sufficiently involved in defining the problems and finding solutions. The research suggests that there is a need for a collaborative process of problem definition and solution-finding.

In some families with SN children, siblings may take on the parental role, which can be difficult or a new challenge and source of encouragement. Strohm (2002) was the sibling of a sister with cerebral palsy. She explained that siblings are often placed in distressing situations that affect their self-image, self-esteem, and mental and emotional domains in adulthood. They often feel isolated, different from their peers, lacking attention in the family, having a duty to help their parents, and similar. There are also siblings who have become more resilient in the face of life's challenges because of the SN child in the family. Siblings of SN children must have sufficient opportunities for support in all areas, including the home, school, peer groups, and special support groups for siblings of SN children. They should also be involved in information and decision-making about their SN siblings.

Practitioners' approaches to vulnerable families of SN children

By *practitioners*, we refer to all professionals who support families of children with special needs in a specific setting, such as social workers or social pedagogues.

Kodele and Mešl (2016) are of the opinion that working with families with multiple challenges brings risk and uncertainty, which can be overcome by creating opportunities to co-create new outcomes. In contrast, Starčević et al. (2016) argue that it is necessary to act as engaged as possible, striving to be sensitive to the specifics of individuals.

Bauer and Wiezorek (2016) analysed how a social worker approached a family in which the mother was in distress because she was unable to care for her child properly. They found that the mother's vulnerability increased rather

than decreased with the social worker's intervention. From this, they gave guidance that the approach to the parents should be adapted to find their areas of strength. A positive attitude can be used to show them the way forward and to accompany and support them in this. They stressed that practitioners should understand and mitigate the vulnerability of such families by urgently changing their approach toward greater sensitivity.

Restoux (2010) provides guidance that families can draw new strength from 1) having enough information and knowledge, 2) finding ways to express their fears, 3) being listened to, understood, and supported by relatives in overcoming their pain, and 4) being able to seek help, for example from a psychologist or a psychotherapist, when the burden of stress and exhaustion is more pronounced.

Knitzer and Lefkowitz (2006) summarised the approaches to possible forms of family vulnerability into four pillars. These guidelines for practitioners derive the following: 1) promote healthy and effective parental reactions to complex risk factors, 2) implement interventions that explicitly address parental risk factors, 3) establish a network of needed services for SN children, and 4) address the specific needs of families. As necessary strategies, they list:

- ensuring that families with lower socio-economic status are included in support projects that improve the chances of healthy development of the SN children,
- providing intensive interventions to help and support the family as early as possible,
- monitoring the mental state of mothers and young children in order to intervene as early as possible in the case of possible depression in the mother,
- involving the whole family in support and assistance projects,
- developing local community-based approaches,
- setting up schools for parents and/or groups providing information for families, etc.

Resilience is a modern concept that can be used to prevent or intervene in families facing serious life challenges. According to Kiswarday (2013), it involves the ability to adapt and be flexible in the face of adversity. Walsh (2008) suggests that the concept of resilience can be especially useful for families with SN children, as it allows them to gather more strength during difficult times and respond with courage, resilience, and a solution-seeking attitude. In addition, Maddi (2002) found that an individual's belief in their ability to influence, control, and be deeply involved in life events, as well as seeing change as a challenge that contributes to further development, can enhance their capacity for

resilience and flexibility. Therefore, life resilience and flexibility are essential for families with SN children to adapt quickly and easily to changes.

Razpotnik et al. (2017) researched and implemented assistance for vulnerable groups. In their case, they implemented housing loss prevention activities within the framework of the Association for Help and Self-Help of the Homeless, the so-called Kings of the Street Association. From their work, we can see an important principle of focusing on sources of strength and seeking an optimal balance between structure and flexibility of support, which can be transferred to families with SN children. From their research, two recommendations are derived: 1) aid and support organisations should be more coordinated and integrated with each other, and 2) they should be focused on the families' livelihoods. Razpotnik et al. (2017) have, among other things, designed family support so that volunteers enter the family field in a sensitive way and thus come closer to understanding the family's needs and making positive changes. Their guidelines are important in terms of finding practitioner balance and making judgments on how not to break trust with families and find appropriate forms of support for them. Equally important is their experience that families have shared important information (e.g., where to buy cheap clothes) by meeting each other over coffee. In the field of special needs, this can be done similarly by creating spaces and opportunities for people to come together and share information on current issues related to SN children.

Research problem and research questions

The research problem in this study is to explore how the forms of the vulnerability of families with SN students in the research sample influenced the reactions of practitioner workers as they pursued the primary aim of action research (AR) to promote the social skills of students with SN.

The research questions that emerged from the study are:

1. In what forms did vulnerability appear in students' families?
This question aims to identify the different forms of vulnerability that families with SN students experienced in the context of the study. This could include economic vulnerability, social isolation, a lack of support, etc.
2. What approaches did practitioners use to reduce perceived vulnerability?
This question explores the strategies practitioners use to address the forms of vulnerability identified in the first research question. The goal is to identify effective approaches to reducing perceived vulnerability.

Methods

Participants

The AR (Plavčák, 2020) included 12 students with special needs, namely, a mild intellectual disability with associated problems (e.g., emotional and behavioural problems, attention deficit disorder). They attended an adapted educational programme with a lower educational standard, from 1st to 5th grade.

In the new research problem presented here, we included the families of these students in the sample (i.e., 12 families). Most of them lived in difficult life circumstances, such as poverty, unemployment, and with health problems. In addition to families, the sample also included professional workers who most often taught the students, mostly the class teachers of these students, other teachers, and a counsellor (i.e., seven professionals).

At the time of the action research, the author of this article was in the role of consultant and implementer of activities to promote students' social skills. Currently, as a researcher, she reanalyses the data from the action research diary and updates it with new results.

Instruments

The basic material of the analysis was the action diary of the AR (Plavčák, 2020). In addition, it included approaches to promote students' social skills (e.g., counselling conversations, art-based help approaches), monitoring the progress of students' social competences, and the cooperation of parents and professionals.

For a new research problem, we added new instruments: Analysis Table 1: evidence of the occurrence of forms of vulnerability in students' families, and Analysis Table 2: reactions of professionals to the vulnerability of students' families. Both analyses were made based on data from the beforementioned action diary.

Research design

The AR (Plavčák, 2020) was carried out in the school year 2013/14, and an action diary was established.

For the new research problem, two qualitative analyses of the action research diary were conducted: 1) a qualitative analysis of the characteristics of students' families (attention to possible forms of vulnerability) and 2) a qualitative analysis of the cooperation between professionals and parents (attention to professionals' responses to perceived vulnerability).

In the first qualitative analysis, Table 1 was formed, in which specific forms of vulnerability in students' families were identified. From the data, the

percentages of the occurrence of a specific form of vulnerability were calculated, as well as the minimum, maximum, and average number of forms of vulnerability per student.

The second qualitative analysis recorded professionals' responses to perceived vulnerabilities in Table 2. The results were then interpreted as suitable approaches to addressing various forms of vulnerability in the families of students with SN.

Results

First, we present the main result of the AR (Plavčák, 2020) as the foundational framework for subsequent analyses: nine out of 12 students demonstrated at least minimal progress in their social development.

As a novel qualitative analysis, we first provide Table 1, which addresses the following question: In what forms did vulnerability appear in students' families?

Table 1
Incidence of forms of vulnerability in students' families

Forms of vulnerability	Students:											
	1	2	3	4	5	6	7	8	9	10	11	12
At least one parent is unemployed.	x	x	x		x	x	x		x		x	x
The family lives in difficult socioeconomic conditions.	x	x	x		x	x	x		x		x	x
One or both parents have mental health problems.	x	x	x		x	x	x		x		x	x
One or both parents are not sufficiently involved in the child's upbringing.		x		x	x	x		x	x	x	x	x
Parents express helplessness in understanding or educating the SN child.		x		x	x	x			x	x		x
There are three or more children in the family where the SN child lives.	x				x					x	x	x
Parents find it challenging to respond to the school's invitations.		x							x	x		x
The SN child is in a foster family.					x	x						
One or both parents are of foreign origin.					x							
The child's education is inconsistent.				x								
There is violence in the family.												
Siblings of an SN child are burdened.												

- Legend:*
- 1=Student 1, 2=Student 2, etc. (for data protection reasons, the names of the students are hidden).
 - An 'X' indicates that the type of vulnerability indicated is present in the student's family. Where there is no 'X', the vulnerability is not present in the family.

The following percentages of vulnerability occur in the families of the students in the research sample:

- 75.00% of the families face unemployment and live in difficult socio-economic conditions;
- 75.00% of the families have at least one parent with a mental health problem;
- In 75.00% of the families, at least one of the parents is not sufficiently involved in the upbringing of the child;
- 50.00% of the families express a lack of support in understanding or raising the SN children;
- 41.66% of the children live in families with three or more children;
- 33.33% of the parents needed several invitations and calls from the school to come for a talk;
- 16.66% of the families are foster families;
- 8.33% of the families have a parent of foreign origin;
- 8.33% of the families have an inconsistent education.

In none of the families was there any suspicion of violence among siblings or their being overburdened.

The results show that for most families in the research sample, the vulnerability was either the parents' unemployment or their mental or other problems. Half of the families expressed helplessness regarding understanding or educating the child. From the author's experience of implementing AR in these groups, she observed that vulnerability in terms of sensitivity and complexity of the situation was evident in most of the students' families, which made the social learning processes very difficult. As seen in Table 1, the students' families showed between one and eight forms of vulnerability, with an average of five forms of vulnerability per student. The result shows a pronounced incidence of vulnerability in the students' families involved in AR.

The second qualitative analysis answers the following question: What approaches did professionals use to reduce perceived vulnerability?

Table 2 shows how professionals responded to the perceived vulnerabilities of students' families. Due to the co-participation of the article's author among the professionals, the professionals' reactions in Table 2 are written in the 1st-person plural.

Table 2*Professionals' reactions to the perceived vulnerabilities of students' families*

Forms of vulnerability	Professionals' reactions
One or both parents are unemployed.	Within the team, we discussed our observations about what the family need. Then, when opportunities arose to participate in projects or when volunteer associations and donors became involved in the school, we helped by making the family aware of possible forms of support. If the family agreed, we began the process of providing support.
The family lives in difficult socioeconomic conditions.	
One or both parents have mental health problems.	We talked to parents in a way that was understandable, clear, and sensitive. At all stages of help and support, we renewed agreements or checked that they were still valid. Sometimes, we arranged for two practitioners to speak with the parents simultaneously to present issues or solutions from different perspectives. Parents were asked for their opinions on the students' problems and difficulties. We talked to parents in a relaxed atmosphere and asked them about their well-being and work at home. In addition, we worked on building trusting relationships with them.
One or both parents are not sufficiently involved in the upbringing of the SN child.	Parents were invited to the school in various ways: by phone, in writing, and for more complex and persistent problems, together with the Social Work Centre. Families were involved in the school on various activity days (e.g., we organised a joint hike, a welcome party, etc.).
Parents express their helplessness in understanding and/or educating their SN child.	We advise parents in a sensitive way on a particular issue where they feel powerless (e.g., we advise them on how to be consistent in their parenting). We were careful not to interfere too much with the integrity of the family. We provided counselling at a pace that the family could manage and based on the currently available solutions.
There are three or more children in the family where an SN child lives.	Having more children in the family meant additional expenses for food, bills, and education. Problems were more intense when more children needed more educational or medical attention. Parents were counselled as much as possible on a concrete level, with concrete guidance and information, in a sensitive way (as described above).
Parents are invited to the school for an interview, but they only come after several invitations and phone calls.	Non-response is one of the most challenging forms of non-cooperation. Therefore, we documented all phone calls and sent invitations by post. In parallel, we reported to the Social Work Centre to intervene if the problems persisted.
The SN child is placed in a foster family.	In two cases where students were placed in foster care, the vulnerability was evident in the expectation of consequences for the child due to separation from parents or trauma inflicted by parents. Considering these assumptions, we stood by them and offered them help.
One or both parents are of foreign origin.	The child was in a foster family, and we did not meet her parents at school. However, she was talking to us about them. She showed significant vulnerability and a great deal of confusion. The team found that she did not have a model of appropriate behaviour. Based on this finding, we were able to understand her better and advised the foster parents to teach her basic life skills.
The child's education is inconsistent.	Inconsistent education was evident in one student. It may have been a case of permissive parenting, as the student was raised by her grandparents due to her mother's frequent absence. We advised the mother to be more consistent in her upbringing. We also talked to the grandparents.

The results show that professionals have a sensible approach to all forms of identified vulnerability in students' families. Sensibility is reflected in the following approaches:

- Parents were accepted as equal partners in helping and supporting students.
- Solutions were co-created with parents; we listened to their suggestions and worked together to find the most appropriate outcomes.
- We set up a respectful and relaxed atmosphere for our meetings with parents, allowing time and space for parents to say how they feel and what they need.
- The team's proposals were presented in an easily understandable manner and, where necessary, in tandem.
- We were creating trusting relationships with parents.
- Families were included in activity days (e.g., sports days).
- Parents were given specific advice based on their problems, taking into account their individual pace and the options available to them.

Discussion

This paper highlights vulnerability as an aspect from which new insights can be drawn from AR (Plavčák, 2020). Additional qualitative analysis suggests that the families in the research sample are vulnerable in many ways, mainly due to unemployment, psychological problems, and other disorders of the parents, but also due to their helplessness when it comes to understanding the child's difficulties and meeting educational demands. Since the aim of the AR (Plavčák, 2020) was to promote social skills, the role of parents was very important. Professionals were sensitive to any form of vulnerability so that they could still do their best to contribute to their children's social development. The sensitive approach embraced both a broader, inclusive climate (Lena, 2016) and a trusting, co-creative relationship with parents. We welcomed them as equal partners in the journey towards improving their children's social skills and looked at them holistically, taking into account their well-being, needs, desires, strengths, and similar factors. As Bauer and Wieszorek (2016) note, we adapted our approach, constantly looking for their strengths. We also encouraged them when it was most difficult, so they did not give up. We did not see families as vulnerable or weak. We were aware that families have many of the problems identified by Walsh (2016) and that challenges in their child's social development are just one of them. We responded with commitment (Starčević et al., 2016) by finding projects and donors to improve their material situation.

We did not forget the foster families either. In our sample, two students from foster families needed emotional support due to their different emotional and behavioural patterns. In these students, the strong influence of their biological parents, who were persons with mental health problems, was evident: these students lacked educational guidance, for example, how to communicate appropriately, how to solve problems, and how to manage conflicts.

In the AR (Plavčák, 2020), attention was also paid to the siblings of SN children in case they were overwhelmed with their care (Strohm, 2002), but this did not prove to be a problem for the families. The siblings did help the family, but their role did not go beyond their strengths. However, they did receive attention and were included in activity days (e.g., a joint hike) or other forms of cooperation with families in the school.

There was no suspicion of violence in the sample of families studied. Had this been the case, we would have responded appropriately according to the established protocol.

The included families with SN children did not exhibit sufficient resilience and resistance to psychological problems, as noted by Kiswarday (2013); in most cases, they surrendered to the flow of life and lost a sense of control over their lives. Many remained in a particular emotional phase due to SN children, such as the denial phase or the values crisis phase (Trtnik, 2007), and only a minority were committed to finding solutions (Gantar, 2009). Additional stress was caused by concerns about the child's behaviour, as Sagadin (2013) also found in her study.

As professionals, we provided the families sensitively with information and knowledge, listened to their fears, and, if necessary, advised them to consult a psychologist or psychotherapist, as Restoux (2010) suggested. In this way, we mitigated their vulnerability while promoting their resilience and resistance. In addition, we helped to strengthen the attitude that life events can be influenced (Maddi, 2002).

The forms of the vulnerability identified in families with SN children certainly influenced parents' responses, complicating the process of developing students' social skills in the sense that we professionals were largely responding to mitigate vulnerability rather than directly providing strategies to develop social skills. Nevertheless, the AR's good results show that 9 out of 12 students made progress in social skills, from which I conclude that our responses to vulnerability were effective, albeit indirectly, in influencing a positive result.

Conclusion

From the findings of AR (Plavčák, 2020) and the further evidence of the vulnerability of families with SN children and the way professionals respond to them, it is concluded that a sensitive and tailored approach to parents is the basis for achieving educational goals for students. In the case of the AR (Plavčák, 2020), the goal was to promote students' social development, but these findings can also be applied to other goals in the school setting.

Sensitivity requires training in listening, counselling, and carrying out activities with a high degree of empathy. The sources of help we find for families must be discussed with them to reach a consensus and agreement. The findings show that working as a team is very important in this process, as it makes observations of families more holistic and the help and support more varied. Ultimately, creating an inclusive, collaborative, and relaxed climate is a responsibility that involves the entire school community; therefore, it is wise to plan a sensitive approach at the strategic level of the school, not only towards parents but in all interactions (e.g., between professionals, between management and professionals, between students). A sensitive approach is all-encompassing as a general principle for all relationships.

For further research, it makes sense to examine more samples of families with SN children to determine what forms of vulnerability are present and what approaches professionals have used to mitigate them. The presented findings cannot be generalised, but further research in this field could provide a more comprehensive picture. New research in this field will, among other things, provide answers to the vulnerability due to the post-Covid-19 epidemic of the present time.

The paper provides guidance to professionals to be attentive to the needs and challenges faced by families with SN children. By identifying what families need and what burdens them, they will be able to adapt their approach accordingly. This means that they will demonstrate their sensibility by partnering with parents on an equal footing, collaborating on solutions, creating a relaxed and trusting climate, engaging in joint activities, allowing sufficient time for communication, and presenting ideas (or even materials) in an understandable way, among other ways. Professionals can reflect on whether their actions are increasing or decreasing the vulnerability of families and evaluate their approach as a team. Of course, it is essential to remember that help and support also depend on the parents' cooperative attitude and assertive posture. When this is not possible, and the problem-solving process does not work in the child's best interests, appropriate external institutions should be included in due time.

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