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# SYSTEM GUIDES AS THE KEY TO CHANGE: GROUNDED THEORY OF EXPERIENCES OF FAMILIES AND CHILDREN WITH MENTAL HEALTH ISSUES

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## Abstract

**Introduction.** Supporting children and adolescents with mental illness in the Czech Republic is hampered by a fragmented care system, long waits and weak inter-institutional coordination. From the viewpoint of social work and social medicine, a *guide* is crucial for continuity of care, empowerment and active participation of families.

**Aim.** To examine how the presence or absence of a guide shapes families' ability to navigate services, stabilise their situation and access resources, and to propose a theory-based model underscoring the systemic importance of this role. The study was funded by the University of South Bohemia (GA JU 133/2024/S) and approved by the ZSF JCU Ethics Committee (No. 018/2023).

**Materials and methods.** Qualitative grounded theory study drawing on 46 in-depth interviews with children aged 11-18 with mental disorders, their parents and social workers. Open, axial and selective coding identified key meanings and relationships informing an emergent model centred on the guide.

**Results.** Without a guide, families reported heightened emotional distress, disorientation and stigma, exacerbated by systemic fragmentation and poor coordination. With a guide, orientation improved, parental competence strengthened, trust in services increased and continuity of care became more likely. A paradigmatic process model describes movement from crisis to stabilisation through guided support and inter-agency linkage.

**Conclusions.** The guide is not an ancillary add-on but a pivotal mechanism that reduces isolation, restores trust and promotes mental well-being. Institutionalising and supporting this role – together with continuity and interdisciplinary coordination – should be a priority for child mental health policy and practice in the Czech Republic.

**Keywords:** mental health, children and adolescents, social work, guide, case management, continuity of care, grounded theory, Czech Republic

## INTRODUCTION

The provision of support for children with mental health issues and their families necessitates a comprehensive, coordinated and sustainable care system. The starting point for effective intervention is continuity of care, which has repeatedly been shown to be a key factor influencing health outcomes, stability and overall quality of life for families. Research has demonstrated that consistent and reliable care, particularly during the transition from child to adult services, can mitigate the likelihood of acute hospitalisation and enhance families' capacity to navigate the healthcare

system [1]. Conversely, disruptions in continuity, caused for example by a change of provider or institutional transition, have been shown to lead to a deterioration in health and a breakdown in support relationships [2, 3].

The primary challenges to maintaining continuity predominantly encompass the fragmentation of the system, the variability of health insurance, frequent changes in the child's placement, and inadequate coordination between health, social, and educational services [2, 4]. In many cases, parents themselves assume the role of care coordinator, a situation which frequently results in feelings of isolation and overload [2]. In the

contemporary support system, a notable progressive and innovative element is the role of the guide, also known as the peer support worker. These workers utilise their personal experiences with mental health issues (or the care of a child) to provide emotional support, practical advice and, most importantly, hope and understanding. Their unique position affords them the ability to build trusting relationships with families, guide them through the system, and help them cope with difficult situations [5]. The work of these organisations is closely linked to the recovery model, with a focus on providing support to individuals as well as on cultivating a more widespread culture of change within the system.

The transformative potential of family peer support is particularly pronounced. Parents who have themselves experienced caring for a child with mental health difficulties often become agents of change. They share their experiences with other families, connect different segments of services, and contribute to the creation of a supportive environment [6]. The role of these institutions in developing value-based alliances between families and institutions is also significant [7].

In the context of family adaptation, research findings indicate that families typically undergo phases of uncertainty, deliberation, and eventual acceptance, striving to achieve a balance between caring for the child and fulfilling their own needs [8, 9]. The family's strategies can be categorised as follows: the establishment of boundaries, vigilance, the enhancement of assets, and, in certain cases, defensive or coercive tactics in response to overload [10]. The empowerment of parents has been identified as a pivotal strategy in overcoming systemic barriers, including but not limited to inadequate access to services and stigmatisation [11]. Programmes that are designed to enhance the parental role have been shown to have the greatest impact when they are supported by organisational leadership, have qualified and motivated staff, and are able to adapt to the specific needs of families [12, 13]. Across the system, it is evident that authentic change necessitates inter-agency collaboration, structural support, and a flexible approach to the local context. The implementation of such policies is complicated by cultural and institutional differences, as well as the absence of uniform standards. It is therefore necessary to work simultaneously at the policy, service and community levels [13, 14].

The insights indicate that the provision of support for families with children experiencing mental health issues cannot be regarded as a task to be undertaken by individual actors. Rather, it is imperative that this support is grounded in a systemic, family-oriented and participatory approach. Such an approach would empower these families to better cope with challenging situations and enhance the quality of life for all members of the household.

## AIM

To examine how the presence or absence of a guide shapes families' ability to navigate services, stabilise their situation and access resources, and to propose a theory-based model underscoring the systemic importance of this role. The study was funded by the University of South Bohemia (GA JU 133/2024/S) and approved by the ZSF JCU Ethics Committee (No. 018/2023).

## MATERIALS AND METHODS

The present study was conducted using a qualitative design and the grounded theory method. The objective of the current study was to develop a theoretical model of the experience of support, barriers and change among children with mental health difficulties and their families, including the perspective of social workers. The selection of grounded theory was made on the basis of its capacity to reveal underlying processes, patterns and relationships directly from field data, thereby enabling a more profound comprehension of complex experiences across system actors. The research sample comprised 46 in-depth interviews with three distinct groups of informants:

- Children and adolescents with mental health issues (n = 33) (aged 8-18, predominantly girls, various diagnoses including anxiety, eating disorders, suicidal tendencies, etc.).
- Legal guardians (parents) of children with mental health issues (n = 3)
- Social workers working in the field of child and youth care (n = 10)

The selection of informants was deliberate, with a view to ensuring a comprehensive coverage of various models of support, types of mental health issues and different regions of the Czech Republic.

The data presented herein was collected through in-depth interviews conducted according to a pre-prepared script, which was designed based on relevant literature and pilot interviews. The interviews concentrated on areas of difficulty, experiences with seeking and obtaining help, barriers and sources of change, cooperation between institutions, and reflections on needs within the system. The interviews were conducted in a secure and private setting, with adherence to ethical principles, and the consent of legal guardians was obtained.

All interviews were recorded and subsequently transcribed verbatim.

### *Data analysis*

The analysis was conducted in three phases according to the principles of grounded theory:

#### **1. Open coding:**

The texts were divided into meaningful units, which were then assigned codes that captured the essence of the

message. The coding was performed manually, with the support of qualitative analysis software.

## 2. Axial coding:

The codes were then grouped into higher categories and subcategories according to similarity and relevance to the research questions. The relationships between categories were identified (e.g., facilitating and impeding factors of change, system influence, importance of key personnel, etc.).

## 3. Selective coding:

Following a comprehensive analysis of all interview transcripts, a **central category** was identified, and a conceptual model was formulated that incorporates key dimensions of experience across various groups. Theoretical saturation was achieved by repeatedly comparing new interviews with existing categories and themes.

The analytical validity of the study was strengthened by triangulation of data (comparison of statements across groups), team consultations, and repeated code review. A selection of illustrative quotes was made in order to represent the breadth and depth of the findings.

All procedures were approved by the Ethics Committee of the Faculty of Health Studies, Jan Evangelista Purkyně University in Jindřichův Hradec, No. 018/2023. Participation in the study was anonymous and voluntary. Written informed consent was obtained from all participants and, where necessary, from their legal guardians.

### *Limits*

Notwithstanding the fact that the study provides a comprehensive insight into the experiences of children with mental health issues, their families, and social workers in the Czech care system, it is imperative to consider several significant limitations that may have a bearing on the interpretation and generalisability of the findings. The primary constraint pertains to the dimensions and composition of the research sample. The majority of respondents were children and adolescents, with only a relatively low proportion of parents participating. This may have implications for the complexity of the family perspective and the degree of triangulation of data from different angles. Concomitantly, it can be hypothesised that families who were willing to participate in the research may have been more active or motivated to seek support than the general population, which may lead to a certain selection bias. A further limitation pertains to regional restrictions, with respondents predominantly originating from selected regions of the Czech Republic. It is acknowledged that these regions may exhibit variations in terms of service availability, local conditions, and the degree of interdisciplinary cooperation. Consequently, it is not possible to extrapolate the results to the broader population of children with mental health difficulties and their families across the Czech Republic. The research

was grounded in a qualitative design and a methodological approach to theory development that emphasised the collection of exhaustive data and the subsequent analysis of subjective experiences. Nevertheless, this approach does not permit quantitative measurement of the extent or prevalence of individual phenomena. The interpretation of data may also be influenced by the subjectivity of the researchers, although increased attention was paid to triangulation, team consultations and reflection on research procedures. Finally, it should be noted that some of the respondents' experiences were influenced by current changes in the care system, such as the introduction of new services or projects at the time of the research. This may have had an impact on their perception of support, service availability, and their perception of barriers and opportunities for change.

## RESULTS

### *Central category: Guide as the key to system transformation*

A comprehensive analysis of 46 semi-structured interviews with children, parents and social workers was conducted to identify the key experiences and processes that structure the experience and management of mental health problems within the care system. The initial phase of the research involved the utilisation of open coding, a method of data segmentation that involves the division of information into fundamental units of meaning. These units were then subjected to a process of focused coding, a technique that entails the classification of these units into more elevated categories. Theoretical coding subsequently led to the identification of a central phenomenon – the role of the guide – which represents a fundamental variable in the system, enabling change and stabilisation of the situation of families and children.

#### *1. Emotional and practical burden on families*

A recurrent theme that has been identified through the analysis of interview data from parents and children is that of intense emotional distress, uncertainty and feelings of isolation experienced during the initial interaction with the system:

«I felt helpless. Every day I went to work and all I could think about was what was happening to him. I stopped sleeping, I felt guilty that I had neglected something.» (parent)

This phenomenon is often accompanied by feelings of stigmatisation, guilt, and a paucity of clear information. Concurrently, the child's challenges are frequently compounded by adverse reactions from their peers and societal institutions that underplay the severity of their difficulties:

«When the psychologist saw that I was self-harming, she said I should instead focus on studying. It didn't help.» (child)

### 2. *System barriers: fragmentation and lack of continuity*

The data unequivocally demonstrates that the care system is perceived as fragmented and challenging to navigate. Reports have repeatedly emerged of protracted waiting times, instances of responsibility being deflected, and inadequate communication between institutions:

«The system. Waiting times, paperwork, passing responsibility between institutions.» (parent)

«Children often fall between the cracks of the system.» (social worker)

The absence of coordination and continuity has been demonstrated to result in a deterioration in the child's clinical condition, as well as secondary traumatisation of families by the system.

### 3. *The guide as a transformative element of support*

The role of the guide, i.e. a guide worker who provides orientation within the system, connects individual care components and provides emotional and practical support, is considered essential in the statements of all participants:

«One social worker helped me the most. She spoke to us as people, not as cases. She recommended a support group and helped arrange an individual plan at school. Without her, I wouldn't have known what to do.» (parent)  
«There was a lady there who referred me to a therapist, who came every week.» (child)

The presence of a guide has been demonstrated to have a calming effect on the situation, thereby enhancing parental skills and reducing feelings of isolation. Recent studies have indicated that this role has a significant impact on the likelihood of successfully coping with difficulties and ensuring continuity of care.

### 4. *Process model of change: from crisis to stabilisation*

Through the analysis of the experiences of parents, children, and staff, a process model of change in the care system can be reconstructed:

- **Crisis phase:** Initial symptoms and increasing difficulties, accompanied by uncertainty, fear and feelings of guilt.
- **Seeking help:** Unsuccessful attempts to find support often lead to resignation unless the family finds a guide.
- **Orientation and stabilisation:** The guide helps with orientation in the system, connects resources, provides support, and promotes the skills of both parents and children.
- **Adaptation and change:** Both the family and the child acquire new coping strategies, actively use available resources, and gradually achieve greater autonomy and stability.

### 5. *Exceptions and nuances*

The data, when examined on an individual basis, appears to indicate a clear correlation between the

absence of formal guidance or contact with the system and a significantly elevated level of frustration, as well as a higher incidence of repeated crises. Conversely, in circumstances where a guide is available to provide continuous and relational support, the system is perceived as safer and more accessible.

### 6. *Emerging theories*

The analysis of interview data has resulted in a proposed theory that places the role of a guide – i.e. a guide worker, case manager or peer support worker – at the centre of the entire system of care for children with mental health issues. This role has been identified in the statements of parents, children and social workers as the central mechanism that enables structural and emotional barriers in the system to be overcome and creates the conditions for real change in the family's life situation.

The interviews reveal that the care system is often perceived as fragmented, confusing and burdened by a number of administrative and communication barriers. Families and children often report feelings of disorientation, social isolation, and a sense of being overwhelmed not only by the manifestations of mental illness themselves, but also by the secondary burden associated with identifying appropriate support services. The initial encounter with the system is often characterised by feelings of uncertainty, fear, and guilt. Concurrently, a significant proportion of actors encounter stigmatisation or trivialisation of their difficulties by those within their immediate social circles or by institutions. In such circumstances, the presence of a guide who assumes the role of a liaison between the family and the fragmented system of services can prove to be a pivotal turning point.

The role of the guide is not only to provide practical information and assistance with navigating the network of services, but above all to build trust, provide emotional support and strengthen the skills of both parents and children. The role of the guide is to serve as the primary individual to whom the family can voice their concerns, thereby facilitating the identification of their fundamental needs and the mobilisation of pertinent resources, including support groups, experts, school counselling services, and community organisations. Regular and trustworthy contact with the guide has been demonstrated to lead to the stabilisation of the situation, the restoration of a sense of security and an increase in trust in the care system. The guide also facilitates coordination between different institutions and supports the family in the decision-making process, contributing to increased chances of successfully overcoming difficulties and preventing repeated crises.

This facilitated change manifests itself not only in the management of the current crisis, but also in the development of new strategies, the strengthening of autonomy and the overall transformation of roles and relationships within the family and in relation

to services. As the family unit gains greater stability and competence, it begins to navigate the system more actively, utilising available resources with less dependence on the guide and transitioning into a partner role in the support process. The role of the guide gradually diminishes, and the natural support network – family, school, community – assumes a more prominent position. The long-term implications of this are twofold. Firstly, there is a change in the individual situation of the child and their family. Secondly, there is the cultivation of institutions that, thanks to this experience, are able to better reflect the individual needs of clients, coordinate care and support the participation of all those involved.

The central tenet of this theory posits that the pivotal factor for positive change is not the nature of the service or the specific diagnosis, but rather the presence or absence of a trusted guide. The existence and functionality of such a role within the system has been demonstrated to result in accelerated stabilisation, enhanced satisfaction with the system, and an overall improved prognosis for

the child and family. Conversely, the absence of this role often results in disorientation, a sense of despair and a cycle of crisis situations. The theory thus highlights the need to systematically develop and support the role of the guide in the care system, as it is this role that enables existing barriers to be overcome, resignation to be transformed into active coping and positive change to be initiated not only at the level of the individual and the family, but also at the level of the entire support system.

The creation of a conceptual framework for change in the care system was enabled by the synthesis of statements from three distinct groups of actors: children, parents, and social workers. The resulting theory posits the role of the guide as a pivotal actor who facilitates the overcoming of structural and relational barriers, stabilises the family situation and activates available resources. In consideration of the findings, a paradigmatic model was developed (see Figure 1), which encapsulates the primary relationships between the causative factors, intervening conditions, strategic approaches, and the consequences of support.

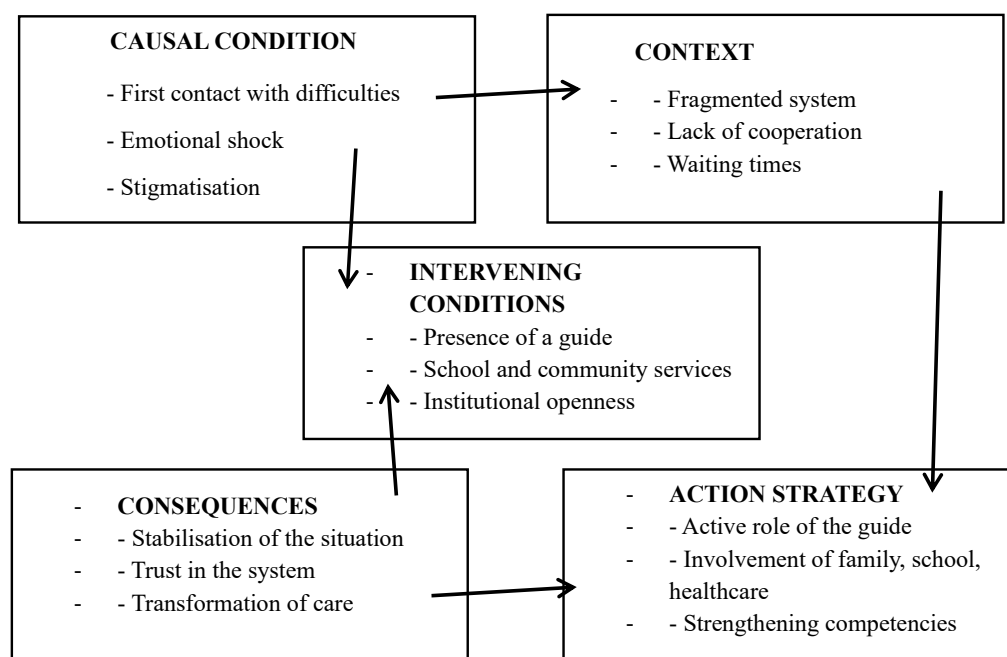


Figure 1. Paradigmatic model of support for families of children with mental illness.

A paradigmatic model was created (Fig. 1) following an analysis of data in accordance with established theory. This model captures the key relationships between the conditions, strategies and consequences of support for children with mental health difficulties and their families. This model integrates the experiences of all three groups of actors – children, parents and social workers – and demonstrates the dynamics of change in the care system. The focus of this text is on the role of the guide, who is responsible for helping to overcome barriers and activate positive change. The model is predicated on five fundamental elements:

#### 1. Causal conditions

The primary motivation for individuals to engage with the care system is often precipitated by a substantial crisis within the family unit, typified by perplexity, trepidation, dearth of information, and frequently accompanied by stigmatisation. It is evident that these circumstances engender a considerable emotional burden, thereby determining the urgency of the need for support.

#### 2. Context

The respondents described the system as fragmented, confusing, and poorly coordinated. The structural barriers that

exist within this system are of particular significance. These include waiting times, the shifting of responsibility, and a lack of interdisciplinary cooperation, which collectively serve to significantly complicate orientation and access to assistance.

### 3. Intervening conditions

A pivotal intervening factor is the presence of a guide – a professional or peer worker who provides emotional and practical support and connects the individual parts of the system. The role of the family is foundational to the success of the intervention and the family's capacity to manage challenges.

### 4. Action strategy

The primary strategy for effecting change can be considered to be the active involvement of a guide who assists the family in navigating the system, supports the development of parenting skills, and initiates cooperation between the family, school, healthcare and community services.

### 5. Consequences

The presence of a guide has been demonstrated to contribute to the stabilisation of the situation, the restoration of trust in the system, and the gradual increase in the family's autonomy. Conversely, in cases where this role is absent, resignation, recurring crises and a general feeling of helplessness persist.

## DISCUSSION

This study contributes to the extant knowledge in the field of care for children with mental health issues by demonstrating the crucial role played by a guide – whether in the form of a guide, a social worker, or a peer support worker – in the process of change. The results of the study show that the presence of a trusted guide is instrumental in enabling families to effectively navigate the multifaceted demands of the care system and proactively address the emotional and organisational challenges they face.

A recurrent finding is that families frequently experience a state of crisis, uncertainty, and isolation in the initial phase. This finding aligns with the extant literature [10], which demonstrates that the responsibility of caring for a child with mental health challenges can lead to diminished perceptions of control, heightened stress reactions, and a state of exhaustion. The findings of the study demonstrate that the disruption of continuity of care, fragmentation of the system and inadequate coordination between services are the primary factors contributing to a deterioration in health and secondary traumatisation [3, 4].

The role of the guide as a stabilising and transformative element of support is of the utmost importance. The programme offers practical guidance within the system, as well as emotional security and reinforcement of parental skills. This finding is consistent

with international research on the benefits of peer support and guide-based support, which demonstrates that individuals with personal experience of mental illness or caring for a child can establish trusting, and respectful relationships with families [5, 6]. Research indicates that when families are provided with such continuous and personalised support, the situation is shown to calm down, internal resources are developed, autonomy is increased and a positive relationship with services is built [11, 13].

The study also reveals that positive change occurs mainly in cases where there is open and interdisciplinary cooperation between the actors in the system – i.e. where the guide connects the family with the school, health, and social services. This finding is consistent with the conclusions of research study [7], which posits that a lack of systemic change and the active involvement of all segments will result in an absence of sustainable progress in the area of children's mental health.

From an implementation perspective, it is crucial that the role of the guide is not perceived as supplementary, but as an integral part of the support system. This position has the potential to contribute to the cultivation of a value-based approach grounded in trust, participation and long-term cooperation. As previously mentioned in point 15, the effective performance and long-term sustainability of peer workers is contingent upon their recognition, integration and support within organisations.

## CONCLUSIONS

The present study offers a comprehensive overview of the experiences of support, barriers and change among children with mental health difficulties, their families, and social workers. This overview is derived from a qualitative analysis guided by grounded theory. The findings indicate that, despite certain positive developments, the majority of children and families seeking assistance encounter numerous systemic barriers, including protracted waiting periods, ambiguous service continuity, inadequate coordination, and insufficient information. These obstacles frequently result in feelings of helplessness, frustration and resignation among both clients and professionals.

However, the analysis also confirmed that there is potential for change if there is a guide or a care coordinator in the system who can safely guide the family and child through the available support options and provide them with the necessary human and practical support. Open communication and cooperation between the school, family, and health/social services also play an important role in this context. However, it is important to note that positive changes are often only partial and unstable unless they are supported in the long term by a functional system and a multidisciplinary approach. The results of the study highlight the need for systemic change in the area of child mental healthcare, particularly in strengthening

multidisciplinary cooperation, accessibility and coordination of services, and in preventing stigmatisation. It is imperative to cultivate the role of a guide who will serve as a nexus, integrating the disparate components of the system and ensuring the seamless continuity of care and support for the family throughout the process.

**Prospects for further research.** In terms of future research, it is important to continue examining the experiences of various actors, focus on the effectiveness of specific models of cooperation, and identify ways to overcome obstacles in the care system. A synthesis of these findings has the potential to contribute to the enhancement of the quality of life of children with mental health issues and their families, as well as to the improvement of the work of professionals in this field.

### FUNDING AND CONFLICT OF INTEREST

The research was funded by the University of South Bohemia in České Budějovice (project reg. no. GA JU

no. 133/2024/S) and approved by the university ethics committee ZSF JCU no. 018/2023.

### COMPLIANCE WITH ETHICAL REQUIREMENTS

All personal data collected during this study were processed in accordance with Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation, GDPR). The research was funded by the University of South Bohemia in České Budějovice (project reg. no. GA JU no. 133/2024/S) and approved by the university ethics committee ZSF JCU no. 018/2023.

### AUTHOR CONTRIBUTIONS

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## Резюме

### ПРОВІДНИК У СИСТЕМІ ЯК КЛЮЧ ДО ЗМІН: ОБҐРУНТОВАНА ТЕОРІЯ ДОСВІДУ СІМЕЙ І ДІТЕЙ ІЗ ПСИХІЧНИМИ РОЗЛАДАМИ

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**Вступ.** Підтримка дітей та підлітків із психічними розладами в Чеській Республіці ускладнена фрагментованістю системи допомоги, тривалим очікуванням та слабкою міжінституційною координацією. З точки зору соціальної роботи та соціальної медицини, роль «провідника» є ключовою для забезпечення безперервності допомоги, розширення можливостей та активної участі сімей.

**Мета.** Дослідити, як наявність або відсутність провідника впливає на здатність сімей орієнтуватися в системі послуг, стабілізувати свою ситуацію та отримувати ресурси, а також запропонувати теоретично обґрунтовану модель, що підкреслює системне значення цієї ролі. Дослідження фінансувалося Південночеським університетом (GA JU 133/2024/S) і схвалене Етичним комітетом факультету охорони здоров'я та соціальної роботи (№ 018/2023).

**Матеріали та методи.** Якісне дослідження з використанням методу обґрунтованої теорії, що базується на 46 глибинних інтерв'ю з дітьми віком 11-18 років із психічними розладами, їхніми батьками та соціальними працівниками. Відкрите, осьове та вибіркоче кодування дозволило виокремити ключові смисли та взаємозв'язки, які сформували модель, центровану на ролі провідника.

**Результати.** За відсутності провідника сім'ї повідомляли про посилення емоційного напруження, дезорієнтацію та стигматизацію, що ускладнювалося системною фрагментацією та слабкою координацією. За наявності провідника покращувалася орієнтація, зростала компетентність батьків, підвищувалася довіра до служб і зростала ймовірність безперервності допомоги. Парадигмальна процесуальна модель описує шлях від кризи до стабілізації через підтримку провідника та міжвідомчу взаємодію.

**Висновки.** Провідник – це не допоміжна опція, а ключовий механізм змін, що зменшує ізоляцію, відновлює довіру та сприяє психічному благополуччю. Інституалізація й підтримка цієї ролі – разом із тяглістю та міждисциплінарною координацією – мають бути пріоритетом політики й практики охорони психічного здоров'я дітей у Чеській Республіці.

**Ключові слова:** психічне здоров'я, діти та підлітки, соціальна робота, провідник, управління випадком, безперервність допомоги, обґрунтована теорія, Чеська Республіка

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