

English summaries – Chapter 1– 40

From the anthology

Children are Next of Kin – Do We Dare Listen to Them?

Nka Children as Next of Kin 2025:2 - Extract



2025 Swedish Family Care Competence Centre™

EDITORS: Rosita Brolin, Ritva Gough, Lennart Magnusson, Elizabeth Hanson

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Editors

Rosita Brolin

Ritva Gough

Lennart Magnusson

Elizabeth Hanson

This anthology is a contribution from experts in the field of Children as Next of Kin. This means that it is based on scientific evidence and/or established experience. The authors are responsible for the content and conclusions of their respective chapters.

English summaries – Chapter 1-40 from the anthology Children are Next of Kin – Do We Dare Listen to Them?

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EDITORS Rosita Brolin, Ritva Gough, Lennart Magnusson, Elizabeth Hanson

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English summaries – Chapter 1 – 40

Children are Next of Kin and Young Carers

1. Children as Next of Kin Are Rights-Bearers

Monica Gustafsson-Wallin

Monica Gustafsson-Wallin is a social worker with many years of experience working with children's rights within both the public sector and civil society. She has worked as an administrator in Region Sörmland and has been involved in Västra Götaland region's work on children's rights as next of kin. She has also collaborated with civil society organisations, other regions, and municipalities on issues relating to children's rights. She currently works independently as a strategic developer, educator, and lecturer.

Summary

Being a rights-bearer is not the same as being a passive recipient of others' kindness, protection, or care. It means being seen—and seeing oneself—as equal to others, with an awareness of one's own worth and dignity. In contexts where children are next of kin, this perspective calls on adults to view the child both as an active agent and as someone in need of protection and care.

This chapter explores how adult perceptions of children and their rights affect the ability of children as next of kin to exercise those rights. Three central concepts are discussed: the child perspective, the child's perspective, and the child rights perspective. All three influence how adults can understand and practically apply children's rights in relation to children as next of kin. The chapter also presents examples of how a child rights-based view can offer decision-makers and professionals both an ethical compass and pedagogical guidance in prioritising the needs of these children.

The chapter highlights dilemmas professionals may face when supporting children as next of kin, such as when key adults and professionals disagree on the child's right to information, advice, or support, or when the child resists participation. In conclusion, the author encourages the reader to reflect on how adult perceptions, and prevailing societal views of childhood, shape the way we recognise children as next of kin as rights-bearers with individual needs.

2. Physical and Emotional Abuse During the First Year of Life: Systematic Infant Mental Health Work with Early Adversity – Identification, Assessment and Intervention

Catarina Furmark

Catarina Furmark is a doctoral student at Karolinska Institutet. Her research focuses on parent–child interaction, parental representations, and experiences of becoming a parent. She is a licensed psychologist and works in Child and Adolescent Psychiatry in Luleå, Region Norrbotten. She also supervises and teaches in areas including developmental psychology, attachment theory, and the DC:0–5 diagnostic classification system.

Summary

Infants are highly dependent on their caregivers. Young children living with a parent suffering from serious mental illness, or where there is partner violence, are particularly vulnerable. Infants can show signs of posttraumatic stress as early as three months of age. In the event of the parent also exhibiting symptoms of posttraumatic stress, parental capacity can be compromised. The infant is more likely to show more severe symptoms of trauma and run higher risk of being abused if the primary caregiver is suffering from PTS. It is important to note that poor mental health does not necessarily equal poor parenting. However, several studies have found a link between mental illness, intimate partner violence and long term negative developmental consequences for the child.

Infants are exposed to traumatic events more often than older children—nearly half of all children affected by trauma are under the age of six. International studies show that 23 percent of children aged 6 to 36 months have witnessed violence between caregivers. A Swedish study found that 19.7 percent of schoolchildren in Sweden had been physically abused by a caregiver. However, there is a lack of data regarding infants and toddlers in Sweden.

A comprehensive assessment should always precede any decision how to best intervene when an infant shows signs of trauma. One systematic way to conduct such an assessment is by using the DC:0-5; Diagnostic classification of Mental Health and Developmental Disorders of Infancy and Early Childhood. As a framework for the infants' rights, the "Declaration of Infant Rights" by the World

Association for Infant Mental Health can be used. Particularly pertinent to the case presented in this chapter are resolutions number five; "The Infant has the right to be protected from neglect, physical, sexual and emotional abuse, including trafficking" and six; "The Infant has the right to access professional help whenever exposed directly or indirectly to traumatic events". A common assumption is that infants are too young to remember traumatic events, or to display any symptoms. In fact, infants have their own unique, non-verbal capacity to communicate – however, they are unable to put their experiences into words. As professionals, we are the infants' voice. We can shine a light on the infants' situation, needs and rights. Children have the right to be nurtured, loved, safe and protected from violence and abuse.

In this chapter, a case is presented, focusing on diagnostic issues and actions necessary to provide effective treatment for an infant exposed to trauma and her parent. Different perspectives and diagnostic considerations in the formulation of the case will be considered.

3. The Infant as Next of Kin

Maude Johansson

Maude Johansson is a Senior Lecturer in the Department of Psychology at Linnaeus University. She is a licensed psychologist, licensed psychotherapist, specialist in clinical psychology, and teacher and supervisor in psychotherapy. She has extensive clinical experience from child and adolescent psychiatry and primary care, as well as experience teaching professionals.

Summary

Symptoms of depression during pregnancy or postpartum are similar to those of depression at other times in life. Common features include feelings of shame and guilt, a lowered mood, thoughts of being inadequate as a parent and unable to care for one's child. Becoming a parent has been likened to a life crisis with adjustment difficulties such as depression and anxiety. For most, the symptoms are transient, but many women develop postpartum depression. Depression not only affects the new mother but also the relationship with the partner and other family members. Most importantly, research has shown that depression during or after pregnancy can seriously disrupt the mother–infant attachment, which is critical for the infant's

development. If left untreated, prolonged maternal depression increases the risk of medical and psychiatric issues in the child later in life. Identifying and treating women with depression during pregnancy is therefore an important step in protecting the mental health and development of the infant. Despite extensive research, there are limited resources dedicated to detecting and treating depression during pregnancy. Early diagnosis of depression during pregnancy, together with access to subsequent medical and psychological treatment, could contribute to more cost-effective care by reducing the need for long-term treatment postpartum and preventing later consequences of mental illness for the woman and child.

4. Children as Next of Kin and Young Carers

Rosita Brolin

Rosita Brolin holds a PhD in Caring Science, a Master of Science in Disability Studies, and bachelor's degrees in Caring Science and Educational Science. She has a professional background as a nurse and teacher. She works as a researcher at the Swedish Family Care Competence Centre and at the Department of Health and Caring Sciences, Linnaeus University. Brolin is a member of the editorial team of this anthology.

Summary

The concept of Children as next of kin (in Swedish Barn som anhöriga) is mainly used in Sweden, while the term Young Carers (in Swedish Unga omsorgsgivare) is mainly used in international contexts. This chapter highlights the differences between the two Swedish concepts Children as next of kin, and Young Carers. Some Children as next of kin take on, or are assigned, a responsibility to look after, provide care, help or support to one or more family members, or other persons who are close to them. These children can be defined as Young Carers. However, this does not apply to all Children as next of kin.

The chapter, which is based on research findings, begins with the definitions of the two Swedish concepts for Children as next of kin, and Young Carers. A case description illustrates what everyday life can look like for Children as next of kin when they do not have extensive caring responsibilities. This is followed by a case description that illustrates what everyday life can look like for a Young Carer.

In the background section, the author summarises twelve years of research on Young Carers and the risk factors identified in the literature, such as negative impacts on education, social life, health, and well-being. The section also includes an overview of political developments from the past six years, including new laws, regulations, and ongoing policy work.

After the introduction and background, the author presents current research that has focused on the differences between being a Young Carer and being a Child as next of kin without extensive care responsibilities. Research findings from Sweden and France are presented. Based on the young people's life situation and caring responsibilities, they are divided into three groups: Young Carers; Young people as next of kin without extensive care responsibilities; Young people who are not next of kin. Comparisons were made between the groups in terms of gender distribution, ethnic background, caring tasks, level of care activities, impact on schooling, perceived health and well-being. Both Young Carers and Young people as next of kin without extensive care responsibilities reported lower levels of health-related quality of life than Young people who were not next of kin. A noticeable result in both studies was that mental ill-health was significantly more common in the Young Carer group, compared to the other two groups. The Swedish study also showed that many Young Carers do not receive any support.

The chapter concludes with reflections on the findings, what we can learn from them, and how this knowledge can be used to develop preventive support to reduce the risk of long-term negative effects on young people's social lives, education, health, and well-being.

The aim of the chapter is to contribute knowledge about the differences between being a Young Carer and being a Child as next of kin without extensive caregiving responsibilities.

5. “I Don’t Want to be a Second Mum” – Identifying Young Carers’ Responsibilities

**Anna Amilon, Ulrika Järkestig Berggren, Ann-Sofie Bergman,
Johanna Thulin, Kerstin Arnesson, Mats Anderberg**

Anna Amilon is a social worker and doctoral student in Social Work at Linnaeus University. Her doctoral thesis explores how young carers experience their caring responsibilities and their interactions with social services, as well as how social services assess children’s caring responsibilities.

Ulrika Järkestig Berggren is a Docent of Social Work at Linnaeus University. For many years, she has conducted research on children’s living conditions and societal support for parenting. Central themes in her research include children as next of kin and children’s caring responsibilities within the family.

Ann-Sofie Bergman is a Docent of Social Work at the Department of Social Work, Stockholm University. She has a background as a social worker with practical experience of social work with children and their families. Within the field of children as next of kin, she is currently conducting research on young carers.

Johanna Thulin is a social worker and Senior Lecturer in Health Sciences at Kristianstad University. Her research concerns, among other things, children’s exposure to violence and opportunities for participation in social services practice.

Kerstin Arnesson is a Docent of Educational Science and Senior Lecturer in Social Work at Linnaeus University. She has worked for many years in social science research and conducts research on children’s caring responsibilities within the family and on violence in close relationships.

Mats Anderberg is a social worker and Docent of Social Work at Linnaeus University. His research interests focus primarily on adolescents with substance use problems and on early interventions for children and young people.

Summary

The chapter describes the (in)visibility of young carers in Swedish legislation, the challenges they may face when growing up, and how professionals within social services can identify them and their needs. Children who are young carers are defined as children who take on responsibility to provide care for one or more family members beyond what is typically expected of their peers. Despite the social services’

statutory responsibility to meet children's needs for protection and support, children's care responsibilities are often overlooked. Which is reinforced by a lack of tools and knowledge on how to identify these children. The problem partly stems from the fact that children's care responsibilities are not acknowledged in Swedish legislation. Children are primarily considered as next of kin in need of protection rather than as active caregivers.

Many of these children live in environments where the parent's needs or problems take precedence, which can lead to the child's own needs being ignored. Caregiving responsibilities can negatively affect a child's physical, mental and social development, for example through stress, feelings of isolation and poorer school performance. At the same time, some children may experience positive effects, such as maturity and a sense of contributing to the well-being of the family, especially if the responsibility is shared with the parent or other adults in the household. This illustrates the importance of developing safety nets and strategies to identify and support young carers.

The chapter also presents an ongoing research project that aims to develop and implement an assessment tool to identify young carers in social services' child welfare investigations. The results so far show that children's responsibilities encompass a wide variety of tasks, from practical household chores to more emotional tasks, and that the degree and nature of responsibility affect how children experience their situation. Social workers describe how the tool has contributed to increased knowledge about young carers' situation and well-being in connection with child welfare investigations. A picture emerges of young carers as a vulnerable and invisible group who are at risk of losing their right to a safe and nurturing childhood. Ensuring their needs are recognised requires better tools, targeted support, and stronger legislation. Furthermore, we need to see these children as actors with unique needs for both protection and support, and the importance of a holistic approach to making their situation visible in the welfare system.

6. Young Carers Who Provide Help and Support to Friends with Health-Related Conditions

Rosita Brolin

Rosita Brolin holds a PhD in Caring Science, a Master of Science in Disability Studies, and bachelor's degrees in Caring Science and Educational Science. She has a professional background as a nurse and teacher. She works as a researcher at the Swedish Family Care Competence Centre and at the Department of Health and Caring Sciences, Linnaeus University. Brolin is a member of the editorial team of this anthology.

Summary

The term Young Carers (in Swedish Unga omsorgsgivare) is most often associated with children who provide care, help or support to a family member who has a health-related condition. However, research has shown that many young people take on caring responsibilities for friends. In this chapter, the term “friend carers” is used to describe this group. Examples include young people who engage in late-night chats with a distressed friend that cannot sleep, ensure a friend gets to school and eats every day, or live with a constant fear that their best friend will commit suicide.

This chapter is based on research findings. The introduction highlights that children and young people who care for friends are not included in current Swedish or international definitions of the terms Children as next of kin (in Swedish Barn som anhöriga) and Young Carers (in Swedish Unga omsorgsgivare).

The introduction emphasises the importance of friends' support for children who have a disability, long-term illness or mental ill-health. A case description illustrates the everyday life for an adolescent that provides care to a close friend.

In the background section, results from the last fifteen years of research are presented on how extensive caring responsibilities can affect the life of young people, both short-term and long-term. For example, their ability to help and support can make them feel an inner strength, and an increased self-confidence, but in the long run the caring role increases the risks of negative impact on their own health and well-being.

The main part of the chapter draws on one European and one American study about adolescents who care for friends with health-related conditions. The author describes the types of caregiving activities these young people undertake, the level of

responsibility they assume, and how their caregiving affects their own lives—including schooling, health, and well-being. The studies show that the most common type of care provided was emotional support. These friend carers felt a deep sense of responsibility and often made themselves available day and night. While the role gave them a positive self-image, it also led to stress, anxiety, and fear—sometimes resulting in mental health issues of their own. These young carers reported lower levels of health-related quality of life and general health than both peers with no caregiving role and those caring for family members. Most of them lacked support from adults entirely.

The chapter concludes with reflections on the findings, and how this knowledge can be used to make this group of Young Carers visible and to give them the support they want and need.

The purpose of the chapter is to shed light on the level of caring responsibility of the young friend carers, the impact on their schooling and perceived health, the support they have access to and the support they feel they need.

Do Children as Next of Kin Have the Same Conditions as Other Children in Sweden?

7. A Law Came About to Protect and Prevent! – Implementing Legislation Based on the Best Interests of the Child

Monica Gustafsson-Wallin

Monica Gustafsson-Wallin is a social worker with many years of experience working with children's rights within both the public sector and civil society. She has worked as an administrator in Region Sörmland and has been involved in Västra Götaland region's work on children's rights as next of kin. She has also collaborated with civil society organisations, other regions, and municipalities on issues relating to children's rights. She currently works independently as a strategic developer, educator, and lecturer.

Summary

In this chapter, experiences are shared from how two Swedish regions – Region Sörmland and Västra Götaland Region (VGR) – have worked from a child-rights-based view of children when implementing chapter 5, section 7 of the Health and Medical Services Act. The author describes how these regions have developed processes and projects that either supported or complicated the implementation of the law.

Initially, implementing child's rights as next of kin in healthcare faced several challenges. Healthcare staff expressed uncertainty and resistance, especially those working with adult patients who felt uncomfortable talking to children. Lack of resources, the need for clear guidelines, and insufficient support from leadership were also barriers. Successful implementation required a clear focus on children's rights and best interests; prioritised even over adults' concerns and ingrained routines.

With this approach, Region Sörmland carried out a development project in palliative care. The project provided increased knowledge on how a new law can be translated into everyday routines. The services developed, among other things, guidelines and improved the environment for the child as next of kin. However, follow-ups revealed

that maintaining these efforts over time proved difficult once project funding ended, a challenge also noted in VGR.

It is now widely recognised that when children as next of kin are acknowledged, it supports not only the child's well-being but also the health and rights of the patient and the entire family. Nevertheless, healthcare professionals still report challenges, including persistent time constraints and inconsistent awareness among staff and managers regarding children's rights and needs in this context.

Thus, we need to broaden our perspective and support children as next of kin not only based on the law's provisions and limitations but also from an ethical and pedagogical standpoint when meeting patients, children, and the child's important caregivers. Here, cross-professional learning about a child-rights-based view of children, child competence, and increased collaboration in healthcare can make the adults more confident and better equipped as custodians of the child's rights as next of kin.

The author concludes by encouraging reflection on how adult attitudes, and society's broader view of children, affect our capacity to recognise children as rights-bearers. Rights-based work is rooted in relationships: with the patient, the child, their family, and colleagues. Through these relationships, we can help ensure every child's right to health, participation, security, and well-being, now and into the future.

8. Children as Next of Kin – What Can National Registers Teach Us About Health and Socioeconomic Consequences from a Life Course Perspective?

Anders Hjern

Anders Hjern is a paediatrician at Sachs' Children's Hospital and Professor of Social Epidemiology in Children and Adolescents at the Department of Medicine, Karolinska Institutet. Since the mid-1980s, he has conducted research and taught on migration and health with a particular focus on children, and has, among other things, published three textbooks on this theme.

Summary

In a series of analyses, our project group has described the health and socioeconomic living conditions of children as next of kin across the life course. The reports are based on anonymised analyses in the national registers maintained by the National Board of Health and Welfare and Statistics Sweden and regional registers in Stockholm. This chapter summarises the key findings from this work.

During childhood, children as next of kin are more likely to live with a single parent, experience mental health problems, leave compulsory school without qualifications for upper secondary education, and grow up in families with significantly lower-than-average income levels. As adults, they face increased risks of premature death, high rates of psychiatric disorders, and a greater reliance on welfare support.

Outcomes were strongly linked to the severity of the parent's health problems. Children of parents hospitalised for mental illness and/or substance use disorders emerged as the most vulnerable subgroup, with the highest mortality rates, the poorest mental health, and the most disadvantaged social conditions throughout life. This group overlapped substantially with children whose parents died by suicide, violence, or accidents - also marked by particularly poor outcomes.

For children whose parents had physical illnesses, the impact varied depending on the illness's severity. Support efforts for these children should be prioritised in cases of long-term or life-threatening illness.

Children with experience of out-of-home care were identified as an especially high-risk group, with elevated levels of mortality, psychiatric illness, substance abuse,

criminality, economic hardship, and low employment rates in adulthood. These children already had a high level of psychiatric morbidity during their adolescence and this increased risk manifested itself even more clearly in adulthood. The results therefore indicate that these children should have high accessibility and priority to interventions from child and adolescent psychiatry. Methods for effectively identifying and treating mental health problems - in the special context that out-of-home care entails - need to be developed and disseminated in Sweden's municipalities.

Children as next of kin are encountered across many sectors of the healthcare and social service systems. Social services play a particularly crucial role in reaching the most vulnerable children. Psychiatry, including care for addicts, is another important platform for support for children as next of kin. Primary care, including child health care centres and school health care, and child and adolescent psychiatry can also have important roles in supporting children as next of kin. The role of general practitioners as family doctors makes them a natural part of such efforts, not least when it comes to identifying children as next of kin in need of support from social services or child and adolescent psychiatry. To fulfil these children's legal rights to care and protection, broad and coordinated training initiatives are needed across multiple professional fields and services.

9. “Colored” by an Adverse Childhood – The Consequences of Racism for Children in Minority Families

Hussein Hamad, Anna Lundberg, Elia Psouni

Hussein Hamad is a doctoral student in the Department of Psychology at Lund University. He is a licensed upper secondary school teacher in Swedish and psychology and has previously worked with community-based outpatient interventions in socioeconomically disadvantaged areas, including in Malmö. In his ongoing doctoral work, he studies the short- and long-term effects of interventions aimed at reducing the consequences of adverse childhood experiences and childhood trauma.

Anna Lundberg is Professor of Sociology of Law at Lund University and Docent of Human Rights. She holds a law degree, a master’s degree in international law, and a PhD in Ethnicity from Linköping University. In her current research projects, Lundberg investigates local solidarity initiatives seeking to counter an ongoing paradigm shift in migration policy, rights mobilisation, and children’s rights in custody disputes in three different countries.

Elia Psouni is Professor of Developmental Psychology at Lund University and a licensed psychologist. She coordinates the interdisciplinary research profile “Children’s Voices, Rights and Development: Tomorrow’s Practices for a Resilient Childhood” and leads longitudinal and intervention studies focusing on children’s socio-emotional development and psychological resilience. Her research focuses on children’s attachment and position within their network of caregivers—within the family and in other care contexts—and on how sensitive and supportive care can prevent or repair the negative effects of trauma and vulnerability.

Summary

What does it mean for a child to grow up as next of kin in a family with a minority background in Sweden? Through a systemic, developmental psychological and rights-based analysis, we discuss indirect and direct consequences of inequalities that threaten these children's well-being and healthy development, and how children's identity, mental health and prospects are affected.

All children in Sweden have a legal right to be protected from racism and discrimination. Yet, Sweden has received international criticism for insufficient action

against structural inequalities and other manifestations of discrimination that affect children in minority groups. Legislation and educational efforts must be strengthened to ensure equal opportunities for all children, regardless of background. To promote effective action, the UN Committee on the Rights of the Child (UNCRC) has called for detailed data collection on children's ethnic and socio-economic conditions.

The statistics in Sweden are clear: Children with minority backgrounds are significantly more likely to grow up in socio-economically vulnerable areas with limited resources; they make up 78 percent of all children living in these areas and every fifth child with a minority background lives in poverty. The chapter highlights how this socioeconomic vulnerability and other structural inequalities weaken parents' financial stability, mental health, coping and opportunities for responsive parenting, thus harming the family, with consequences spilling over to the children.

In addition to consequences linked to the family's situation, children with minority backgrounds also describe their own experiences of explicit discrimination, microaggressions or exposure to stereotypes in their interactions with both children and adults, particularly at school and in other public places. Adult caregivers (teachers, coaches) often overlook these events, misunderstand their significance, and fail to intervene appropriately.

Long-term exposure to discrimination leads to chronic stress, depression and anxiety, and creates a sense of hopelessness for many. Because of these well-documented effects on children, the American Association of Pediatricians considers racism to be a key social determinant of child health. It is important to remember that children do not choose which families, countries, or times they are born in – the conditions that affect children in families with minority backgrounds are largely due to social structures that neither the children nor the adults in their families alone can influence.

While parental worry about how to protect their children from discrimination and racism can result in increased anxiety and overprotection, studies show that strong family ties, strengthened ethnic and cultural identities, and giving children tools to deal with discrimination, have a protective effect and promote the children's psychological resilience. Attributing the problems with integration to the individual, disregarding the uneven preconditions that exist in society, is incompatible with the extensive scientific literature, counterproductive and very costly for society. It is also in sharp contrast to the commitments Sweden has made through the UNCRC about the equal value of all children. Understanding how structural inequality affects children's development is crucial. By integrating research, legislation and practical measures, the negative effects can be mitigated and a more inclusive and equitable future for children from minority backgrounds can be created.

10. Digital Interventions for Children and Young Adults with Parents Affected by Mental Illness or Substance Use Problems – A Narrative Review

Ola Siljeholm, Tobias Elgán

Ola Siljeholm is a licensed psychologist and holds a PhD in Medicine, specialising in support for relatives of people with problematic substance use. He works at STAD, a competence centre that develops, implements, and evaluates preventive methods within the alcohol, narcotics, doping, tobacco, and gambling field. Siljeholm also works clinically at Stockholm Centre for Dependency Disorders, treating adults with alcohol dependence.

Tobias Elgán, is a researcher at STAD within the Centre for Psychiatry Research and a Docent of Public Health Sciences at Karolinska Institutet. He has worked at STAD since 2010, conducting research on children as next of kin to parents with alcohol or substance use problems, with the aim of developing and evaluating digital support programmes that provide accessible support for young people and strengthen their mental health

Summary

Children as next of kin to parents with impaired mental health or problematic alcohol or substance use face elevated risks of adverse outcomes, including poorer mental health and increased vulnerability to substance use themselves. Studies from Sweden and internationally show that a significant number of children grow up in such environments. To mitigate these risks, both universal and selective preventive interventions are needed. Although most Swedish municipalities offer support, only about 2 percent of affected children receive help, largely due to challenges in identification and recruitment. Stigma and limited availability contribute to health inequalities, particularly in rural areas. This highlights the urgent need for new support programs, with digital interventions showing promising results.

This chapter presents a narrative review of digital support programs for children and young adults (aged 3–25) who are next of kin to a parent with mental illness and/or substance use problems. The reviewed studies evaluated interventions targeting the child, the parent, or the entire family. A literature search was conducted across several different databases.

In total 6772 records were identified. Given the large number of results, a manual search for controlled trials was conducted, yielding 856 unique studies for screening. Finally, 20 references were selected, covering 12 unique digital interventions. These included six interventions targeting children and young people and six aimed at parents. The studies comprised six completed randomised controlled trials (RCTs), two pilot RCTs, one qualitative process evaluation, and eleven study protocols.

Most interventions were based on cognitive behavioural therapy (CBT) and aimed to enhance mental health and self-efficacy in participants. Programs for parents focused on parenting strategies, positive reinforcement, and communication, while those for children and young people emphasised coping strategies, cognitive restructuring, stress management, and social support. Programs that included therapist support tended to achieve better outcomes than self-help interventions, particularly for programs directly targeting young participants. Interventions that incorporated group discussions and interactive elements showed positive effects on stress, depression, and social support, whereas the sole identified self-help intervention had more limited effects. However, the self-help intervention reached individuals who had never sought support before, likely due to the accessibility and the possibility of anonymity. A notable observation was the overwhelming majority of female participants (90–95%) in both parent- and youth-focused interventions. This reflects previous research on family support programs and raises important questions about how interventions can be designed to engage more men and boys. Co-creating programs with the target audience may help develop more relevant and engaging interventions.

Overall, this review highlights the potential of digital, CBT-based programs to support at-risk children and young people. However, further research is needed to determine the most effective intervention strategies. Future studies should focus on developing interventions in collaboration with the target group, ensuring they are accessible, adaptable, and inclusive for a broader audience.

11. Growing Up with Parental Alcohol Problems: The Situation in Sweden

Mats Ramstedt, Jonas Raninen

Mats Ramstedt is a Docent and research group leader at Karolinska Institutet. He is also Director of Research at the Swedish Council for Information on Alcohol and Other Drugs (CAN). His research primarily focuses on the relationship between alcohol consumption and alcohol-related harm in the population.

Jonas Raninen is a social worker and a Docent of Addiction Science at the Centre for Psychiatry Research, Karolinska Institutet. His research mainly concerns epidemiological studies on how alcohol consumption and alcohol-related harm are distributed in the population.

Summary

There is no established methodology for determining how many children grow up with parents who have alcohol problems. As a result, existing research findings vary greatly depending on the definitions and methods used. A Swedish review found that just over 20 percent of children in Sweden have, at some point during childhood, lived with a parent with alcohol problems, and that 3.5 percent have experienced very serious issues. Although these estimates are rough, they clearly demonstrate the extent and variation of the problem, as well as the sensitivity of the numbers to how the issue is defined and measured.

Children in these families often grow up in unstable and conflict-ridden environments characterised by a lack of care, which increases their risk of developing psychosocial problems, both during childhood and later in life. These children constitute a particularly vulnerable group, regardless of whether the harm stems directly from the alcohol misuse or from interacting risk factors in the child's environment.

Research has shown that socio-economic factors such as low educational attainment and financial hardship increase the risk of vulnerability. Girls are also more likely than boys to report negative experiences, suggesting both greater vulnerability and heightened awareness. Many of these children adopt coping strategies, such as taking on responsibility at home, shielding their parents, or concealing the situation due to feelings of shame and stigma.

Although most municipalities in Sweden offer support services for children in these circumstances, it remains unclear how many are reached. Overall, the existing evidence points to a significant gap between the support that is needed and what is currently provided for this group of children.

12. Children in Refugee Families: A Developmental and Critical Rights-Based Perspective

Elia Psouni, Anna Lundberg

Elia Psouni is Professor of Developmental Psychology at Lund University and a licensed psychologist. She coordinates the interdisciplinary research profile “Children’s Voices, Rights and Development: Tomorrow’s Practices for a Resilient Childhood” and leads longitudinal and intervention studies focusing on children’s socio-emotional development and psychological resilience. Her research focuses on children’s attachment and position within their network of caregivers—within the family and in other care contexts—and on how sensitive and supportive care can prevent or repair the negative effects of trauma and vulnerability.

Anna Lundberg is Professor of Sociology of Law at Lund University and Docent of Human Rights. She holds a law degree, a master’s degree in international law, and a PhD in Ethnicity from Linköping University. In her current research projects, Lundberg investigates local solidarity initiatives seeking to counter an ongoing paradigm shift in migration policy, rights mobilisation, and children’s rights in custody disputes in three different countries.

Summary

The chapter focuses on children in families who have sought asylum in Sweden. From a developmental psychological lens, we explore how insufficient protection and support shape these children's lives, development, and well-being. Anchored in a rights-based perspective, we examine the international legal protection afforded to these children and how this protection is implemented—or fails to be implemented—in the Swedish context. We conclude with reflections on key priorities for the future.

Children develop in close interaction with their caregiving environments, where relationships with emotionally available and responsive adults are key protective factors. Stable and predictable caregiving strengthens children's psychological resilience, while limited access to safety, continuity, or emotional support pose significant developmental risks. These conditions are, in turn, influenced by the broader structural circumstances surrounding the family. Parents' caregiving capacity can be deeply affected by social and economic marginalization, physical and mental health challenges, and the profound uncertainty, social disconnection, and lack of resources that often accompany the asylum process.

Children in refugee families may carry their own traumatic burdens—direct experiences of war and forced displacement that impact their physical and mental health. In addition, they risk being affected by the unprocessed trauma of close adults. This so-called secondary traumatization is well documented in research and must be understood as a consequence of inadequate societal protection and limited access to recovery support. Outside the home, children face further barriers, especially in school, including language difficulties, social exclusion, and discrimination. Children who arrive without their families are particularly vulnerable due to absence of stable caregiving contexts, and many report serious difficulties accessing the help they need.

Despite these challenges before, during, and after displacement, refugee parents strive to remain hopeful, shield their children from further adversity and provide them with a better future. Yet long-term emotional strain can erode parental mental and physical health. Children, in turn, may feel compelled to take responsibility for their family's well-being, reversing the typical caregiving dynamic. However, the dynamics between refugee children, their families, and surrounding societal structures are complex. While such role reversals can burden children and negatively impact their development, research shows that practical contributions—when supported and contextually appropriate—can strengthen children's sense of agency and self-worth. Children's responsibilities must therefore be understood in relation to the family's migration history, asylum context, and cultural expectations of parenting.

In Sweden, refugee children's rights are formally protected through legislation, institutional norms, and everyday interactions in health care, education, and social services. However, the UN Committee on the Rights of the Child has repeatedly criticized Sweden for providing insufficient support to asylum-seeking children. Key principles such as non-refoulement and protection from child-specific persecution are not always respected in the asylum process. Sweden has been urged to take concrete legal and policy measures to ensure children's rights, including improving access to family reunification, health care, education, and protection from discrimination.

Ensuring a safer future for refugee children requires stable caregiving environments and long-term support to mitigate social and psychological risks. In cases of trauma, support must reach both children and their parents. Tailoring interventions to the unique needs of each child and family offers a more just and effective path forward—to reduce both suffering for the children and the economic burden for society.

13. The Covid-19 Pandemic, a Particular Challenge for Children as Next of Kin

Pauline Johansson

Pauline Johansson is a nurse with specialist training in cancer care. She is a Docent of Health Sciences and Head of the Department of Medicine and Optometry at Linnaeus University. Johansson is coordinator of the research network Children as Next of Kin, a collaboration between Linnaeus University, the Swedish Family Care Competence Centre, and the National Board of Health and Welfare.

Summary

The Covid-19 pandemic brought extensive consequences for society as a whole, but particularly for children as next of kin in families affected by mental illness, substance abuse, or violence. Sweden adopted a unique strategy by not fully shutting down society, yet public health measures such as remote schooling, canceled leisure activities, and visitation bans still significantly impacted children's daily lives. This chapter attempts to provide an overview of the situation for children as next of kin in Sweden during the Covid-19 pandemic. Few Swedish studies exist in this area, and it is also important to emphasise that children as next of kin are not a homogeneous group, as their life circumstances and need for support vary greatly depending on the parent's or relative's illness or difficulty, and the child's access to support.

Children as next of kin became even more invisible during the pandemic. Many experienced anxiety, stress, and fear, both of becoming ill themselves and of their loved ones being affected. For children in vulnerable families, existing difficulties were exacerbated, while healthcare staff had limited contact with the children, reducing insight into their living conditions. Children reported increased anxiety, depression, and physical symptoms. Restrictions reduced access to protective factors

such as social relationships and leisure activities, and many lacked trusted adults to turn to when schools were closed, or teaching was conducted remotely. School is an important protective factor, but the pandemic led to increased absenteeism, especially among children in difficult home environments. Remote learning worked differently for different students, some experienced increased stress and loss of control, while others appreciated the flexibility. Children in socioeconomically disadvantaged families were more severely affected, partly due to limited internet access. Many children as next of kin had to take on greater caregiving responsibilities at home, especially when parents' health deteriorated or support services were suspended. They helped with cooking, administering medication, and caring for siblings, all while trying to manage their own studies.

Despite the challenges, there were also positive aspects. Some children experienced strengthened family relationships, more time with parents, and better focus on schoolwork. Digital support formats enabled more children to participate in support groups, especially those who otherwise could not attend physical meetings. However, information during the pandemic was often unclear and not tailored to children as next of kin. Many received their information via social media, which led to confusion. Non-profit organisations attempted to fill the information gap. Access to support for children as next of kin varied greatly across the country, and digital solutions became crucial for reaching children in need of support.

For future crises, coordinated efforts between schools, healthcare services, social services, and the non-profit sector are essential. Children as next of kin must be included and listened to. They need access to age-appropriate information and tailored support. Digital tools must be functional, and staff need competence and technical assistance. Further research is needed on the experiences, needs, and preferences of children as next of kin during a pandemic, to inform the development of effective support models for both everyday life and times of crisis.

Children in Families Where a Family Member Suffers from Mental Illness, Substance Abuse, Other Serious Illness or Disability

14. Children as Next of Kin of Parents Treated in Specialised Adult Psychiatry

Lina Wirehag Nordh, Gisela Priebe, Maria Afzelius, Ulf Axberg

Lina Wirehag Nordh is a licensed psychologist and affiliated researcher at the Department of Psychology, University of Gothenburg. She completed her doctoral thesis on children as next of kin to a parent receiving treatment in specialised adult psychiatry, and on parents of children referred to child and adolescent psychiatry.

Gisela Priebe is Professor of Psychology at Karlstad University, where she also served as Director of the Centre for Research on Children's and Young People's Mental Health and Living Conditions (CBU) between 2021 and 2025. She is a licensed psychologist and psychotherapist specialising in family therapy and has extensive clinical experience from both adult psychiatry and child and adolescent psychiatry.

Maria Afzelius is Senior Lecturer in Social Work at the Department of Social Work, Malmö University. She is a social worker, licensed healthcare counsellor, and licensed psychotherapist specialising in family therapy. One of her current research areas is family work within adult psychiatry.

Ulf Axberg is a licensed psychologist and licensed psychotherapist. He works at VID Vitenskapelige Høgskole in Oslo as Professor of Family Therapy and Systemic Practice. His work has focused primarily on intervention research in collaboration with practice settings, including parenting support for parents within specialised adult psychiatry.

Summary

This chapter focuses on children as next of kin to parents undergoing treatment within specialised adult psychiatry. It highlights that many children grow up with parents diagnosed with a psychiatric condition, approximately one-third of adult

psychiatry patients have children that are minors. Extensive research has shown that these children are at an increased risk of developing mental health issues themselves.

Findings from a national study conducted by the authors showed that children of parents treated for depression, anxiety, or bipolar disorder within specialised adult psychiatry had significantly higher levels of mental health symptoms compared to children in the general population. About one-third of the children were reported to have symptoms severe enough to require treatment of their own. Contributing factors included younger child age and low parental confidence in their parenting abilities. Additionally, the presence of multiple risk factors in the child's environment further increased the likelihood of mental health issues.

The chapter also presents findings on the effectiveness of Beardslee's Family Talk Intervention and Let's Talk about Children. These preventive interventions were shown to reduce the risk of children developing mental health problems and were shown to provide parents with valuable support in their parenting role. The findings support their continued use within specialised adult psychiatry.

Furthermore, the chapter summarises results from register-based studies that examined the implementation of legal provisions in clinical practice– specifically, how many children were identified in adult psychiatry, how many families received child-focused interventions, and how often collaboration occurred with other relevant services. The results indicated that far from all children were identified and that relatively few families were offered support measures.

The chapter aims to disseminate research-based knowledge about this group of children and their life situations, with the goal of improving support for children as next of kin, their parents, and their families within specialised adult psychiatry and related services. The authors conclude with reflections and recommendations for how this can be achieved.

15. Living an Ordinary Life – Yet Not Quite: Experiences of Being the Child of a Parent with Deafblindness

**Moa Wahlqvist, Maria Björk, Karina Huus,
Ann-Sofie Sundqvist, Agneta Anderzén Carlsson**

Moa Wahlqvist is a social educator and holds a PhD in Disability Studies. She works as a researcher at the Audiological Research Centre in Region Örebro County and is an affiliated researcher at the School of Health Sciences, Faculty of Medicine and Health, Örebro University. Her research focuses on health, support services, family life, and working life for people with deafblindness. She is also R&D coordinator at the Swedish National Resource Center for Deafblindness.

Maria Björk is a paediatric nurse and a Docent in Health and Caring Sciences at the School of Health and Welfare, Jönköping University. Her research focuses on everyday functioning among children with long-term illnesses or disabilities, the situation of families, and professionals' caring approaches.

Karina Huus is a paediatric nurse and Professor of Nursing with a specialisation in children and young people. She works in the Department of Nursing at the School of Health and Welfare, Jönköping University. Her research focuses on children's health, children's rights, and participation in everyday life for children with disabilities, as well as siblings as next of kin to people with disabilities.

Ann-Sofie Sundqvist is an affiliated researcher and a Docent of Medical Science specialising in Health and Caring Sciences at Örebro University. She works as a project manager at the Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU). Her research focuses, among other things, on how children and adolescents are given opportunities to make their voices heard regarding their care and treatment.

Agneta Anderzén Carlsson is a paediatric nurse, Adjunct Professor of Nursing Science, and affiliated researcher in Disability and Society at Örebro University. She is also active at the University Health Care Research Center in Region Örebro County. Her research focuses on the health and well-being of children and families, and on life situations involving deafblindness.

Summary

In Sweden approximately 2000 people live with deafblindness. Some of them are parents. Knowledge about what it is like to grow up with a parent with deafblindness is limited. It is important to expand this knowledge, as well as to understand the parents' needs and strategies for parenting, in order to safeguard the child's right to health and development. This is particularly urgent in times of economic austerity, when individuals with deafblindness may be less likely to receive the societal support they need.

In this chapter, we share experiences from children and parents in families where a parent has deafblindness. The chapter is mainly based on a Swedish research project, in which children and parents were interviewed and answered questionnaires about their quality of life, sense of coherence and family climate. The results indicate that these children live ordinary lives – yet not quite. The children described living family lives similar to their peers, taking part in the same kinds of activities. However, they also described how life is different due to their parent's deafblindness. They explained how they feel the need to be present for their parent, helping and protecting them from harm. For example, they put away their toys or return items to their proper place to prevent accidents and to help the parent find things, which they feel creates a sense of security for the parent.

The children also reported emotional effects such as feelings of frustration, compassion and a need for support. Some experienced financial strain due to their parent's disability. The parents described using many strengths and strategies in their parenting, and that they receive support from family, friends, teachers, and others. They are aware that their child might take on a greater responsibility their peers but stress that they themselves do not want the child to take on too much responsibility at home. Some parents expressed that they had not always received the support they needed from society throughout different stages of parenthood, which raises their concerns about their child's right to health and development.

Children of parents with deafblindness have in this chapter been given a voice. Professionals who meet parents with deafblindness should ask whether they have children and assess if those children may need additional support. This is equally important for professionals who meet these children in their everyday environments, such as in schools, student health services, and child health care. In addition, the support needs of parents must be met in order to reduce the risk that the parent's deafblindness negatively affects the child's right to health and development. At times, collaboration between different services may be necessary.

16. Living in the Shadow of a Sibling with Home Mechanical Ventilation and Complex Healthcare Needs

Åsa Israelsson-Skogsberg

Åsa Israelsson-Skogsberg is an intensive care nurse, holds a PhD in Caring Science, and is Senior Lecturer at the Academy of Caring, Working and Welfare, University of Borås. She also works at the Thoracic Intensive Care Unit at Sahlgrenska University Hospital in Gothenburg. Israelsson-Skogsberg completed her doctoral thesis on children's experiences of living with ventilator treatment at home, from the perspectives of the children, their siblings, parents, and personal assistants.

Summary

The chapter describes how everyday life can be experienced and perceived by siblings of children who require home mechanical ventilation (HMV). Sibling relationships can be among the longest and closest relationships in life. Having a sibling who depends on HMV means living close to a child with extensive and complex care needs, often requiring the presence of personal care assistants around the clock. This situation not only affects the child receiving care but significantly shapes the daily life and development of the healthy sibling. Having a sibling with a severe illness often demands much of the parents' time and energy, which in turn influences the healthy siblings in various ways.

The chapter describes and elaborates findings from a research study in which ten siblings, aged 8 to 17, were interviewed about their daily lives. The relationship was described as an "intertwined interaction," a deep connection that links past, present, and future. Through this bond, siblings were shaped into brave individuals who defended their brother's or sister's right to be themselves and championed the value of diversity in society. Their role could be likened to that of a loyal knight -wearing emotional armor while guarding a powerful but vulnerable inner world. This interconnectedness fostered traits such as maturity, empathy, and extensive knowledge. However, it also led to feelings of worry (about their sibling's worsening health and what might happen), concern (about how their parents would cope if their sibling's condition deteriorated further), responsibility (for the sick sibling), having to grow up faster than many of their peers, and experiencing limited time and space with their parents.

To cope with these emotional challenges, siblings used various strategies, which research highlights as important to acknowledge. Studies also emphasise the significance of open and inclusive communication with children about their sibling's condition. Such conversations can positively impact the mental health of siblings, and support interventions focusing on the parent-child relationship can be beneficial.

17. Support Interventions for Children as Next of Kin to a Parent or Other Adult with Neurological Disease or Injury

Linda Gustafsson

Linda Gustafsson is a social worker and holds a master's degree in social work. She works as a licensed healthcare counsellor at Sahlgrenska University Hospital in Gothenburg. She is also the author of children's fiction on the theme of being a child as next of kin to an adult with a neurological illness or injury.

Summary

This chapter provides an insight into the support interventions that can be offered to children as next of kin to a parent (or other adult) who has a neurological disease or injury. Such conditions affect the brain, spinal cord, nerves, or muscles. Some are chronic and may require lifelong specialist care, while others are progressive and potentially fatal.

Being a child as next of kin can have both positive and negative effects. Particular attention should be paid to the needs of children for information, guidance, and support when a parent or close adult has a serious physical illness or injury. The best interests of the child must be considered in all matters affecting them. Children have the right to be informed, to be involved, and to have their voices heard.

I (the author) work at a neurology clinic in which we inform parents on how to support their children. We offer family conversations facilitated by a social worker and a nurse to help families speak openly about the illness. We also use the Family Talk Intervention - a method aimed at preventing mental health issues in children.

In addition, we run a collaboration forum for professionals from different disciplines to continuously improve our support for children as next of kin.

Our goal is to prevent both short- and long-term negative effects on children. Every child of a parent with a neurological condition should be offered the support they need. At present, our interventions are evaluated orally, but we aim to introduce structured written evaluations. We are also developing digital support groups for children as next of kin.

Preventive interventions are needed to reduce the risk of both physical and mental health issues. The methods we currently use are grounded in research and established practice. While they offer a solid foundation, they are not yet complete. For example, we continue to explore how to better reach children whose parents decline the (voluntary) support available.

18. Children as Next of Kin to a Parent or Sibling with Palliative Care Needs

Malin Lövgren, Camilla Udo

Malin Lövgren is Professor of Caring Science with a specialisation in palliative care at Marie Cederschiöld University. Her research concerns families with children who have palliative care needs. A large part of her research involves developing, evaluating, and implementing different types of support for these families or individual family members.

Camilla Udo is a trained social worker, licensed healthcare counsellor, and Professor of Social Work at Dalarna University. Her research mainly focuses on psychosocial support for families when a child or parent has a serious illness, and on how psychosocial support can be integrated into care processes in cases of severe illness.

Summary

Children who live with a parent or sibling with life-threatening or life-limited illness face many challenges. At the same time as they must deal with the fact that a close family member has a serious illness, they are going through an important period of

their own personal maturity and growth. The purpose of this chapter is to focus on these children's life situations and provide recommendations on how to support these children and youths based on research. Studies show that professionals often struggle to talk with children about a family member's severe illness and impending death. There is frequently hesitation and fear that addressing these difficult topics might worsen the situation, rather than help. Research also indicates that children with a seriously ill family member often feel invisible and overlooked – by both healthcare professionals and those in their immediate surroundings. Several factors in healthcare, such as lack of information and communication, increase the risk of mental illness many years after the death of the family member. Support, which we know is beneficial, is therefore important. Today, not all children have access to support on equal terms. In this chapter, examples are given of how support can be developed in health care to make children involved. It also includes suggestions for how local care guidelines can be developed to better include children and promote open family dialogue about the situation and everyone's emotional well-being, something that is protective against psychological problems.

19. Children as Next of Kin When a Loved One Is Being Cared for at the Hospital – Approach and Involvement

Susanne Knutsson

Susanne Knutsson is a Docent at the Department of Health and Caring Sciences, Linnaeus University in Växjö. She is an intensive care nurse and is responsible for the specialist training programme in intensive care nursing at advanced level at Linnaeus University. Her doctoral thesis addressed the importance of children's participation in the situation of a closely related person.

Summary

Visitation restrictions for children visiting the intensive care unit have decreased in recent years as family members increasingly advocate for their children and grandchildren's access, media highlights the importance of family involvement, and research shows the benefits of inclusion – such as feelings of participation and

involvement and reduced suffering. Despite this, both nurses and parents often experience personal fears about children visiting, driven by a desire to protect both the child and the patient. Nurses frequently rely on personal judgment rather than formal guidelines or evidence, and a lack of training in addressing emotional needs and communicating with children at an age-appropriate level further limits children's presence in the intensive care unit. Organisational factors, including restrictive policies, age restrictions, environmental factors, psychological trauma, and infection risks for both the child and the patient, are also persistent and important factors to consider. Despite legal frameworks, such as the Swedish Health and Medical Services Act and the UN Convention on the Rights of the Child, which emphasise children's rights to information and involvement, adapting the care units to be more inclusive for children has been difficult due in part to the aforementioned factors.

This chapter presents a framework for recognising, meeting, and involving children as next of kin. It has been developed through research to ensure that children with a seriously ill or injured family member are identified early and meaningfully included in the care context - thereby reducing emotional distress for both the child and the family. Clinical implications are discussed, including how children wish to be approached, what they consider important, and strategies for ensuring their inclusion. A "take home message" summarises key insights. The chapter is based on research with theoretical underpinnings and has been developed in accordance with children's rights.

In conclusion, this chapter addresses hospital visitation policies, the rationale offered by healthcare providers and guardians for or against children's visits, and children's own experiences. It also provides practical guidance for healthcare professionals on how to involve children as next of kin in a way that supports the well-being of the child, the patient, and the wider family - both now and in the future.

20. “Will dad die now?” – Meeting Children as Next of Kin in Intensive Care

Caroline Hansen

Caroline Hansen is a licensed healthcare counsellor and works at the Department of Neurosurgery, Linköping University Hospital. She is trained as a social worker and holds a Master of Arts degree. She has a particular interest in working with children as next of kin to someone in intensive care and in developing and improving that work.

Summary

This chapter is based on the author’s personal experiences of working with children as next of kin to patients in intensive care, and how relevant theoretical frameworks can be applied in practice. It describes both the challenges and the rewarding aspects of this work, offering a practical perspective on supporting children during a family member’s critical illness. The text outlines how cases typically arrive in an intensive care unit (ICU) and how support efforts are adapted to the ICU setting. The focus is on hands-on practices and reflections from the author's own professional context. It is important to note that approaches may differ across hospitals and intensive care units in Sweden. The chapter includes examples of how healthcare staff can initiate conversations and engage in meaningful dialogue with children. All conversations and quotations are fictional and intended as illustrative examples. It also provides examples of non-verbal and indirect ways of interacting with children in emotionally charged situations. Rather than presenting universal truths, the aim is to offer insight into what a child’s perspective might look like when they are next of kin to a patient in intensive care. The goal is to also provide an enhanced understanding, for both staff and students who will interact with these children or young people, of what they have experienced during or after the intensive care period.

21. Children Who Have Lost a Parent or a Sibling: Grief and Support After the Loss

Rakel Eklund, Josefin Sveen

Rakel Eklund is a Docent of Caring Science and works as a researcher at the Department of Women's and Children's Health, Uppsala University. She is originally a specialist nurse in psychiatric care and completed her doctoral thesis in palliative care on children as next of kin when a parent has a life-threatening illness and receives specialised palliative home care.

Josefin Sveen is Professor of Clinical Psychology at Senter for krisepsykologi, University of Bergen, and Visiting Professor at the Department of Women's and Children's Health, Uppsala University. In several studies, she has investigated how families can best be supported after a loss, how children are affected by losing a sibling or a parent, and she works to improve support and treatment for bereaved children and families.

Summary

Losing a parent or sibling during childhood is a profoundly challenging experience that can affect children in various ways depending on their age, maturity, and previous experiences. Children's understanding of death evolves gradually and is influenced by their cognitive, emotional, and social development. Younger children often have a limited understanding of the permanence of death, while older children and teenagers develop a more in-depth comprehension, which can lead to existential thoughts and feelings of guilt and anger. The loss of a parent can create significant anxiety and uncertainty for children, especially if the surviving parent is also struggling with their own grief. The death of a sibling can lead to feelings of jealousy and guilt, particularly if the deceased sibling had been ill for a long time. Children's grief can manifest as anxiety, sleep disturbances, concentration problems, and somatic symptoms such as stomachaches and headaches. In the short term, grief in children can lead to emotional and behavioural reactions such as shock, denial, anxiety, and fear. Children's grief can also manifest as somatic symptoms such as stomachaches and headaches. Children may also experience intense feelings of guilt and magical thinking, where they believe their thoughts or actions may have caused the death. Sleep difficulties and anger are also common reactions. Grief can impact children's school performance and social relationships, leading them to withdraw from friends and activities they previously enjoyed. In the long term, the loss of a

family member during childhood can increase the risk of mental health issues such as depression, anxiety, and posttraumatic stress. Children who have lost a family member may also find it more challenging to develop close relationships in the future and may experience a lower quality of life. Protective factors that can help children cope with their grief include a safe and supportive family environment, open communication about what has happened, and a stable social network. Involving children in decisions about funerals and memorial services can also foster a sense of inclusion and empowerment. Schools can play a crucial role by providing an environment where the child can take a break from grief and receive support from teachers and peers. Most children need some type of support. There are different levels of interventions, ranging from basic information and social support to professional treatment for those who develop prolonged grief or other mental health problems. Preventive interventions may include psychoeducation about grief and loss, while therapeutic interventions can involve cognitive-behavioural therapy and other therapeutic methods. In summary, it is essential to offer support and treatment to bereaved children to help them manage their grief and reduce the risk of long-term negative consequences in their lives.

22. Children Who Have Lost a Parent to Suicide: Preventing Risk Development and Strengthening a Constructive Grieving Process

**Somaya Ghanem, Anneli Silvén Hagström, Ulla Forinder,
Sofia Grönkvist**

Somaya Ghanem is a social worker and doctoral student at the Department of Social Work, Uppsala University. She previously worked as a counsellor and programme coordinator at BRIS (Children’s Rights in Society). There, she worked with children and their families in both individual and group-based support, particularly when children had lost a parent through suicide.

Anneli Silvén Hagström is a social worker with basic training in psychotherapy, a licensed healthcare counsellor, and a Docent of Social Work. She works as a Senior Lecturer and researcher at the Department of Social Work, Stockholm University. She has a particular interest in children and young people who have experienced

traumatic and stigmatising events, and in their opportunities for storytelling and processing.

Ulla Forinder is a social worker, licensed psychotherapist, and Senior Professor of Social Work at the University of Gävle. She has worked for many years with children and families in traumatic situations and, in the 1990s, helped establish support groups run by Save the Children for children and young people who had lost a sibling or parent through death. Her research is mainly within the field of children and families.

Sofia Grönkvist is a social worker with basic training in psychotherapy and works as Head of Unit at BRIS (Children's Rights in Society). She is responsible for BRIS reception services for children and young people as well as the organisation's training activities. She initiated and developed BRIS's support work for children and families who have lost a parent through suicide and is responsible for that area of work.

Summary

Each year, approximately 400 children in Sweden are affected by a parent's suicide – the ultimate consequence of mental ill health. Life is turned upside down, and the grief impacts the child both acutely and for a long time to come. Moreover, the grief is often complicated by the stigma and the unique circumstances surrounding a suicide, not least through feelings of guilt and shame. A child affected by a parent's suicide often faces a multiple exposure. This arises partly from the loss and its consequences, and partly from difficult events they commonly experienced before the parent died. Some children report life situations that involved violence, substance abuse, and other family troubles. Research also highlights that this group of children have an elevated risk of developing mental health issues and social problems themselves – and even of dying at a young age. With the right kind of support, these risks can be mitigated. According to the Swedish Health and Medical Services Act, society has a responsibility to offer these bereaved children information, advice, and support as part of preventive measures, but it has not yet been established what this support should entail. In 2024, the National Board of Health and Welfare developed support material for the regions to use in improving support for the target group, as many regions lack such support structures. This chapter contributes research and clinical insights into common grief reactions and support that can prevent risk and foster a constructive grieving process. The authors bring both clinical and research-based experience in working with these children, including through BRIS (Children's Rights in Society) support services for children and their parents, which are also discussed in the chapter.

Children in Families with Complex Circumstances and/or Violence in the Family

23. Homeless Families in a Long-Term Perspective – Studying Children’s Homelessness with the Family Service Centre as an Arena

Eva Nyberg

Eva Nyberg is a psychologist with extensive experience of diagnostic and therapeutic family work with very young children in maternal and child health care. Her doctoral thesis focused on migration among families with children and the need for knowledge development among professionals working with children and young people. Central questions in her research have concerned homelessness among families with children and how changes in housing policy affect homeless children, influence children’s roles and family relationships, children’s living conditions, health and development, and how opportunities for support from a family centre are affected by being next of kin.

Summary

This chapter summarises a long-term collaborative project aimed at deepening our understanding of what it means for a family, especially the children, to live without stable housing over an extended period. The project is based in a metropolitan suburb classified as a vulnerable area. This area is characterised by both widespread social problems and a high proportion of families with children. The project involves a partnership between the Family Service Centre’s preventive social services and a research component led by the local Research and Development Unit (FoU).

Homelessness re-emerged a serious problem in Swedish society around the turn of the millennium, following a long period of rather intensive housing production. One focus of the project has been to study what is referred to as the housing search process (*bosökarprocessen*), which encompass the efforts families undertake to secure new housing after losing their home or lacking formal housing for other reasons.

In both research and social work practice, child and youth perspectives have long been absent from discussions about homelessness. The issue has traditionally been

framed as an adult problem, leaving children's experiences overlooked. Yet the housing search process profoundly affects all family members, practically and emotionally, dominating daily life and leading to feelings of exclusion and inferiority.

In recent years, housing has increasingly been recognised as a key issue in debates regarding social inequality and children's health. Sociological research has highlighted how housing insecurity not only affects children from already disadvantaged backgrounds but can also lead to greater inequality later in life. Only in the last few decades have children in homeless families been included in national data collected by the Swedish National Board of Health and Welfare, providing a more comprehensive family-oriented perspective.

A central topic in this project is the so-called secondary housing market for families that are unable to be approved for standard leases, this market has grown significantly over the past decade. It includes collective housing arrangements often characterised by overcrowding. These housing forms present unique challenges for families and especially for children.

Recent case studies have shed light on how homelessness alters roles and relationships within the family and between the family and society. The project emphasises the need for method development in social work related to families navigating homelessness and housing insecurity. One approach explored is compensatory social work, which are interventions designed to support families who lack stable housing and mitigate long-term risks to children's health and well-being.

24. Children with Incarcerated Parents

Åsa Norman

Åsa Norman is a Senior Lecturer and a Docent affiliated with Uppsala University and Karolinska Institutet. Over the past 15 years, she has conducted research and practical work focusing on families affected by imprisonment. She currently leads research projects aimed at scientifically developing and evaluating support interventions for children with incarcerated parents and their non-incarcerated caregivers.

Summary

This chapter constitutes a research overview of existing knowledge, needs and knowledge gaps in relation to support for a specific group of children as next of kin: children with incarcerated parents.

Children with incarcerated parents in Sweden can be considered an invisible group in society that face great risks of both ill-health and marginalisation. The chapter is based on the need for Sweden to allocate resources to support this group of children as next of kin who have a high risk of ill-health and future criminal involvement. Key prerequisites in allocating resources to support these children are knowing how many, and who the children are, as well as having evidence-based interventions. Currently, Sweden lacks the sufficient knowledge and structures to be able to meet these prerequisites.

Swedish and international research consistently shows that children with a parent in prison face greater risks than their peers. These risks span individual, family, and societal levels. Despite this, there are no national systems in place to identify these children, meaning that no reliable data exists on the number of children affected. This invisibility may contribute to the lack of targeted resources and interventions.

Moreover, there is a general absence, both nationally and internationally, of evidence-based interventions specifically developed for this group. In Sweden, the limited support that does exist is primarily provided by civil society organisations. These services are only available in certain parts of the country and typically lack evidence-based tools.

International researchers have called for the development of tailored, flexible, evidence-based interventions that respond to the diverse and complex needs of these children. Effective support must address the child as an individual, the child's relationships with parents or other close adults, and broader societal factors.

Coordinated, multi-agency approaches are likely essential to adequately address this complexity.

The chapter outlines what is currently known about the risks faced by children with incarcerated parents, reviews available research on interventions, and describes ongoing efforts in Sweden to develop evidence-based support. It concludes by proposing how future structures might be designed to identify and support this vulnerable group, and how existing collaboration and intervention models could be adapted to meet their needs.

25. With Parents at a Distance – Challenges for Children in Foster Care

Kerstin Neander, Amanda Angelöw

Kerstin Neander is a social worker and holds a PhD in Medical Sciences from Örebro University. She is employed at the University Health Care Research Center, Region Örebro County. For many years, she has worked with interaction treatment in infant and early childhood families. A recurring theme in her research is children in vulnerable situations.

Amanda Angelöw is a psychologist, holds a bachelor's degree in human Rights Studies, and is a doctoral student in Developmental Psychology at the Department of Psychology, Lund University. Her research concerns children in foster care and is conducted within the project "Children in Foster Care: A Co-Created Research Project on Security, Resilience and Coping".

Summary

In 2023, 18,800 children in Sweden were placed in foster care, meaning that they lived apart from their family of origin for a period of time. Maintaining parent-child relationships during such placements presents a range of challenges. The chapter explores these challenges from multiple perspectives – legal frameworks, theoretical approaches and experiences from placed children, birth parents, foster parents and social workers.

Historically, attitudes have shifted from overlooking the importance of maintaining contact with the child's original family to promoting such contact as inherently positive. While this shift is generally viewed as progress, there is concern that an ideological stance – that contact is always beneficial – sometimes takes precedence over a case-by-case assessment of what is best for the individual child.

The concept of “three-part parenting” is often used in foster care, referring to the shared responsibilities among social services, foster carers, and birth parents. Each party may face unique difficulties in this arrangement: birth parents may feel excluded or inadequate, foster carers may experience uncertainty about the future of the placement, and social workers often work within fragmented systems marked by staff turnover. However, the greatest burden is carried by the child.

To ensure that a child's right to contact with their parents is realised in a meaningful way, both foster carers and social services must provide the necessary support. Even when both the child and the parent wish to maintain contact, these visits can be emotionally charged and difficult to manage in short periods of time.

Children may also express reluctance to visit or show signs of distress after contact with their birth parents. These signals are difficult to interpret and may lead to conflict. On one hand, contact is often encouraged based on the principle that reunification is the ultimate goal of foster care and that maintaining ties is generally in the child's interest. On the other hand, there are situations in which contact may negatively affect the child's mental health and emotional development.

Article 3 of the UN Convention on the Rights of the Child states that “in all actions concerning children, the best interests of the child shall be a primary consideration.” Determining what is in a child's best interest must be done individually and thoughtfully, taking multiple perspectives into account. To fulfill the promises of the Convention, all of us who work with children in foster care must become better at listening to and understanding what the child is trying to tell us.

26. Children as Next of Kin to Violent and Abused Parents

Maria Eriksson

Maria Eriksson is Professor of Social Work at Marie Cederschiöld University. Her research mainly focuses on the significance of different forms of inequality for the political and practical handling of men's violence against women and children. Particular attention is given to issues of parenting and children's rights.

Summary

Children's exposure to violence and their roles as next of kin have long been treated as separate issues—addressed in different forums and often by different groups of researchers and practitioners. This chapter aims to help bridge these gaps in knowledge and practice, and to improve support and interventions for children who are both next of kin and victims of violence. Since the mid-1980s, children who experience violence in their families have received increasing attention. However, the ways in which children have been given attention has changed over time. These children, who have experienced violence, have gone from being perceived as invisible “non-victims” to, after the turn of the millennium, being acknowledged as “victims of violence,” “crime victims,” “plaintiffs,” and “next of kin.” Similarly, violence has been framed variously as a non-issue, a health issue, a social problem, a crime, and -last but not least- as a problem closely linked to the child's status as next of kin. These conflicting perspectives can create a confusing and challenging environment for those seeking to support these children. At present, there are still relatively few methods or intervention models that explicitly recognise children exposed to violence in their role as next of kin. This is especially true regarding children who also act as young carers to a parent who is either victimised or violent. Much remains to be done to develop interventions to protect and support children who are both next-of-kin, young carers and exposed to violence.

27. Children as Next of Kin to Parents Who Have Used or Been Subjected to Violence – Managing Risk and Vulnerability

Åsa Källström, Martina Vikander

Åsa Källström is Professor at the Institute of Behavioural, Social and Legal Sciences, Örebro University. She is originally trained as a social worker and has conducted research since 1997 on, among other things, children's exposure to and experiences of violence, threats, conflict, and crime. The main focus of her research is family violence, how children understand and manage violent experiences, and how society can meet children's needs for professional support.

Martina Vikander is a social worker and holds a PhD. She works as a researcher in the Social Work Unit at Örebro University. She has previously worked in foster care and addiction treatment. Her research interest is feminist violence research, with a focus on men's violence against women and children.

Summary

When one parent uses violence against the other, children are at risk of developing a wide range of behavioral or emotional problems. Social services therefore have a responsibility to protect children against violence if the parents are unable to do so. This chapter deals with children who are next of kin to parents that have used and/or been subjected to violence. While the primary focus is on intimate partner violence between parents, violence directed toward the child is also included. Drawing on current Swedish research, the chapter explores how risk, vulnerability, and protective factors interact in safeguarding children exposed to such environments. It discusses key considerations for assessing and managing risk in close relationships, stressing the dual role of children as both next of kin and victims. Professionals from various fields can contribute to the protection of children through different protective measures. However, such measures do not necessarily yield purely positive outcomes for children. Therefore, it is essential to prevent or limit negative consequences, whether they arise from the intervention itself or from external factors which may limit the intervention's effectiveness.

28. Boys as Next of Kin Victims of Violence

Margareta Hydén

Margareta Hydén is Professor Emerita of Social Work at Linköping University, affiliated Professor of Criminology at Stockholm University, and a licensed psychotherapist. She has also been a Visiting Professor at the University of Manchester. Since the late 1980s, she has worked as a researcher, university teacher, supervisor, consultant, lecturer, and psychotherapist in the field of violence in close relationships.

Summary

This chapter explores the experiences of five boys who responded to repeated violence perpetrated by their fathers or their mothers' partners against their mothers. The concept of "next of kin victims of violence" is introduced to capture the boys' dual position. Both as next of kin and as victims of crime themselves. In Sweden, exposing a child to violence against a close family member is a criminal offense.

The chapter argues that a violent event is best described as a circular process, comprised of three parts or phases: first, the violent act; second, the creation of meaning which is, how the woman, child, and surrounding social networks perceive the violence; and third, how they respond to it.

Four distinct response patterns were identified among the five boys: *protection*, *avoidance*, *confrontation*, and *separation*. These responses were shaped by their efforts to stop the violence and maintain a sense of family responsibility.

The chapter also introduces two key terms: intimate partner violence (violence occurring while the parents are in a relationship) and parenthood violence (violence continuing after the relationship has ended, within the framework of shared parenthood). The boys' narratives include examples of both types, and parenthood violence is described as placing an additional burden on the child in their role as next of kin.

Most of the chapter is dedicated to the presentation and analysis of the boys' stories. The chapter concludes with a discussion and recommendations for support and therapeutic interventions aimed at children in similar situations.

Recognising and Developing Interventions for Children in Need of Support

29. Supporting Children as Next of Kin in Schools and Healthcare Settings

Christine Werner

Christine Werner is a licensed physician and specialist in paediatrics and adolescent medicine and has basic training in cognitive behavioural therapy. She is currently CEO and one of the founders of Stella Child Health and Stella Youth, a clinic for children, young people, and their families in need of support related to mental ill health and neuropsychiatric difficulties.

Summary

Most children and young people live close to an adult they depend on. Some children have several such adults in their lives. If any of these adults experience sleep problems, depression, financial difficulties, addiction, personality disorders, illnesses, or disabilities, it will affect the child in one way or another. The presence of siblings or stepsiblings with health issues or challenging circumstances may also impact the child.

Other risk factors in the child's environment, as well as protective factors and the child's own resilience, influence how the child reacts to what they experience.

It is crucial that adults, especially those working in schools and healthcare, are alert to signs of mental health issues in children. These signs can include sleep problems, changes in appetite, changes in social behaviour, difficulties at school, mood swings, pain, or physical complaints without physiological causes. Behavioural changes, such as social withdrawal or excessive sociability, can also indicate that a child is struggling.

If the adult's ability to care for the child is impaired, this may also cause harm to the child. Therefore, it is important to pay observe parent-child interactions, how communication with the school and healthcare providers functions, and more practical aspects such as whether the child has clean and season-appropriate clothing. Professionals must always remain vigilant for signs of violence or abuse.

Not all children show obvious signs of being unwell or suffering. Nor do all children express their struggles directly. This makes it even more important for school and healthcare staff to proactively ask children how they are doing. This can be done systematically, for example during school health consultations. It is equally important to create a safe and accessible environment where children feel comfortable discussing their difficulties. Student health services can play a vital role in this regard.

By increasing awareness of children's roles as next of kin, professionals can offer earlier support, which may help prevent mental health problems.

In summary, it is essential that adults recognise the signs that a child is unwell or at risk, and that this may be related to the child being next of kin. A holistic view of the child's circumstances, considering various factors in their life, is crucial to providing the right support.

30. “Everyone Thinks That Everyone Knows... but in Reality, No One Knows”: Norwegian Public Health Nurses’ Work in Identifying and Supporting Children as Next of Kin

Marie Dahlen Granrud, Tuva Sandsdalen, Agneta Anderzén Carlsson, Cecilie Ruud Dangmann, Anne Kjersti Myhre Steffenak

Marie Dahlen Granrud is an intensive care nurse, holds a PhD, and works as Senior Lecturer in the Master's programme in public health nursing at the University of Inland, in Norway. Her research mainly focuses on the work of public health nurses, as well as the health of children and young people when they are next of kin.

Tuva Sandsdalen, is an intensive care nurse, holds a PhD, and is Senior Lecturer at the University of Inland, in Norway. She teaches in the master's programmes for advanced specialist nursing and for cancer care and intensive care. She has several years of clinical experience working with children and their relatives. Her research

mainly focuses on quality in health care from the perspectives of patients, relatives, and healthcare professionals.

Agneta Anderzén Carlsson is a paediatric nurse, Adjunct Professor of Nursing Science, and affiliated researcher in Disability and Society at Örebro University. She is also active at the University Health Care Research Center in Region Örebro County. Her research focuses on the health and well-being of children and families, and on life situations involving deafblindness.

Cecilie Ruud Dangmann, is a public health nurse, holds a PhD, and is Senior Lecturer at the University of Inland, in Norway. She teaches in the master's programme in public health nursing and supervises doctoral and master's students. Her research mainly focuses on the health and quality of life of vulnerable groups, such as children as next of kin and children belonging to minority groups.

Anne Kjersti Myhre Steffenak is a public health nurse, psychiatric nurse, and Professor. Her main position is at the University of Inland, in Norway, where she is Programme Director for the master's programme in public health nursing. She is also employed as Professor at the University of South-Eastern Norway. Her main research interests are children and young people, preparedness and infection control, and service research.

Summary

In Norway, the professional role of helseesykepleier (public health nurse) refers to specialist nurses working with children and young people up to age 20, primarily in child health clinics or school health services. The professional role includes promoting health of children and families. As they are embedded in children's everyday environments and meet a large portion of the child population, public health nurses are well-positioned to identify children who are next of kin to parents with serious or long-term illness or disability, and to support those in need. Within the framework of their professional practice, a public health nurse can offer some support, even though in Norway there is no statutory responsibility to have a "child responsible professional" within the municipal health care system, who looks after the child's interests when a parent suffers from a serious illness or has a permanent disability.

Children who are next of kin often benefit from talking to someone outside the family, and public health nurses believe they can fulfil this role. However, they lack formal guidelines for how to do so. Identification of these children is often coincidental, and nurses rely on personal clinical experience to determine what support to offer. While they adapt their interventions based on their knowledge of the individual child, they emphasise the importance of professional collaboration - yet such collaboration is also mostly incidental due to structural and organisational barriers.

Despite uncertainties in their role, public health nurses express a strong ethical and moral commitment to recognising and supporting children as next of kin. They believe collaboration is possible when consent is obtained from children and parents, and that better structures could improve outcomes.

Based on existing literature and professional experience, there is a clear need to develop national guidelines in Norway for identifying children as next of kin and outlining appropriate support services within municipal healthcare. Such guidelines should be implemented in collaboration with all relevant stakeholders. Children as next of kin have a right to receive knowledge-based support - if they want it.

31. ME-WE: The First Large-scale European Initiative to Promote Mental Health Among Adolescent Young Carers

Miriam Svensson, Lennart Magnusson, Rosita Brolin, Elizabeth Hanson

Miriam Svensson is a doctoral student in Health Sciences at Linnaeus University. Her doctoral thesis focuses on health and health promotion among young carers in Sweden. She previously obtained a Master of Science in Health and Lifestyle and a bachelor's degree in Biomedicine.

Lennart Magnusson is a senior adviser and researcher at the Swedish Family Care Competence Centre, formerly head of operations and one of the driving initiators behind the establishment of the centre. He is a Docent at the Department of Health and Caring Sciences, Linnaeus University, and leads several national development and research projects within the centre's field of work, including Children as Next of Kin. Magnusson is a member of the editorial team of this anthology.

Rosita Brolin holds a PhD in Caring Science, a Master of Science in Disability Studies, and bachelor's degrees in Caring Science and Educational Science. She has a professional background as a nurse and teacher. She works as a researcher at the Swedish Family Care Competence Centre and at the Department of Health and Caring Sciences, Linnaeus University. Brolin is a member of the editorial team of this anthology.

Elizabeth Hanson is Professor at the Department of Health and Caring Sciences, Linnaeus University, Kalmar, where she leads the research group “Informal Care, Relatives and Family Caregiving in a Life Course Perspective”. The research group is a research branch of the Swedish Family Care Competence Centre (Nka), where she serves as Scientific Director. She previously served as Chair and Vice-Chair of Eurocarers, where she helped initiate Eurocarers’ working group for and with young carers (2017–). Hanson is a member of the editorial team of this anthology.

Summary

Between five and ten per cent of all children in Europe are young carers. These children provide care, help or support to someone close to them with a health-related condition. The international, EU-funded project *Psychological support for promoting mental health and well-being among adolescent young carers in Europe (ME-WE)* was the first large-scale European project aimed at promoting health and strengthening resilience among young carers aged 15–17 years, also referred to as adolescent young carers. The project consisted of three main activities: (1) systematising knowledge about adolescent young carers, (2) developing and testing a preventive intervention together with adolescent young carers and their stakeholders, and (3) disseminating the project results. The ME-WE project started in January 2018 and ended in June 2021. To ensure that adolescent young carers in different life situations were included, the project was carried out in six countries with varying levels of awareness and support: Italy, the Netherlands, Switzerland, Slovenia, the United Kingdom and Sweden. The project was coordinated by Linnaeus University.

Related to the overall goal of promoting the health of adolescent young carers, the ambition was to enable cross-country comparisons and raise awareness among decision-makers, health and social services, schools, civil society organisations, young people themselves and other relevant actors. This objective was achieved through the various activities of the project. A number of publications, both scientific and popular science, have been published with results from the project. Among other things, the first survey of the situation of adolescent young carers aged 15–17 years in Europe was conducted, which has now been published in an international journal. Furthermore, analyses of policies, laws and safety nets, among other things, have been carried out and contributed to new knowledge. A central component of the project was the development of a support intervention, the ME-WE model, consisting of group meetings and an app for adolescent young carers.

Although the project ended in 2021, work with ME-WE has continued. In Sweden, the Swedish Family Care Competence Centre (SFCCC) and SFCCC’s research group at Linnaeus University are actively working to disseminate and implement the ME-WE model. At the same time, various project results continue to be published and

presented at conferences and related policy events both at national and international levels.

This chapter summarises the various activities and results of the ME-WE project and describes how the SFCCC and SFCCC's research group at Linnaeus University have continued their work after the end of the project period. The chapter concludes with reflections and recommendations on how young carers' situation can be highlighted and what further work is needed to improve their current and future lives.

32. The Joy of Working with Beardslee's Family Intervention/Family Talk – Professionals' Perspectives on the Method

Anita Cederström, Anna Demetriades

Anita Cederström is a psychologist and holds a PhD. She has worked with children and their families in practice, clinically, and in research. Through her public health work on mental health, she became the first person in Sweden to train in Beardslee's family intervention/Family Talk. She has also worked as a university lecturer in pedagogy, psychology, and social work.

Anna Demetriades is a social worker, holds a Master of Arts degree, and is a licensed psychotherapist as well as a teacher and supervisor in psychotherapy. She has many years of experience of working with relatives, both children and adults, in her role as a licensed therapist and as a child representative within psychiatry.

Summary

Part I of the chapter presents an interview study with professionals, most of whom work in adult psychiatry, about their experiences with the Family Talk intervention. The chapter begins with a brief introduction to the method and the existing research surrounding it. The findings show that professionals experience great satisfaction and joy in working with Family Talk. This positive perception is primarily due to the significant changes they observe in families and in the children's situations, the positive feedback they receive from both parents and children, and the sense of

emotional closeness that develops with family members, which makes the work more engaging. The professionals also describe feeling personally energised by using the method. Additionally, they express confidence in the intervention's structured format, which supports them in building meaningful connections with the children.

Part II of the chapter offers an analysis of why Family Talk seems to work well for both families and professionals. The analysis draws on a research study identifying essential components for successful interventions or psychotherapy, regardless of theoretical orientation. These include the conversation leader's empathy, the way the leader relates to the client, the early development of a strong alliance, and the leader's belief in the method. According to the professionals, all these components are present in Family Talk. A central aspect of the method is the facilitator's approach to clients—not as an expert, but with the intention of establishing a subject-to-subject relationship. The parents' personal narratives are given importance, allowing them to share their unique perspectives rather than being reduced to a diagnosis or problem. They are invited to contribute their own views on how their family situation might improve. This respectful and collaborative approach is described as a key factor in the intervention's effectiveness.

33. Participation as a Given: A Development Project Supporting the Rights of Children as Next of Kin Aged 3–6

Janina Fryckholm, Åsa Lundström Mattsson

Janina Fryckholm works at the Allmänna Barnhuset Foundation as project manager for the development project BRA conversations for children aged 3–6. She holds a master's degree in children's Culture and works with issues relating to children, culture, and participation.

Åsa Lundström Mattsson is an authorised social worker and works at the Allmänna Barnhuset Foundation as project manager for the development project BRA, Children's Right as Next of Kin. She has also worked on issues relating to violence against children and is an expert in matters concerning social services work with children.

Summary

This chapter presents experiences and insights garnered from a project conducted by the Children's Welfare Foundation Sweden between 2019 and 2023. The project was funded by the Swedish Inheritance Fund and aimed to develop and adapt the existing Good Dialogues (BRA-samtal) model for a younger demographic. The primary objective was to collaborate with children to create communication tools that facilitate dialogue between children aged 3-6 and staff regarding their needs for information and support, when they are next of kin to a family member facing difficulties, is ill or who has died. As a result of the project, tools were developed to facilitate communication between adults and children, which are based on the rights of the child. The tools were the result of a creative exploratory process in which children participated.

The principle of child participation was crucial to the development process, significantly influencing both the structure and approach of the project. Initial assessments indicated a notable gap in targeted methods enabling preschool-aged children to express their experiences as next of kin, as well as a scarcity of examples involving younger children in research and method development. Consequently, the project emerged as an exploration of largely uncharted territory.

Throughout the project, child participation served dual roles as both a mechanism for quality assurance and as an ethical compass. This led to a dynamic planning process that evolved in response to the children's activities and feedback. A key ambition was to ensure a safe environment for child participation, emphasising autonomy and consistently seeking consent. Additionally, it was essential to remain attuned to the children's emotional states, fostering a creative atmosphere without performance requirements.

The project showed that developmental work with younger children benefits from an openness to diverse modes of expression, including body language, drawing, acting, and storytelling. The children exhibited various ways of conveying their thoughts, utilising forms of expression that resonated with their individual circumstances. They communicated about important issues that affected them, and the communication was clearly enhanced through the use of varied materials and tools.

The collaborative exploration with the children culminated in the creation of a multifaceted tool, accompanied by a structured framework comprising four sessions designed for joint exploration of the child's informational and supportive needs as next of kin. The efficacy of these tools will be evaluated in a researcher-led pilot study scheduled for 2024-2025.

34. Why is Participation and Feedback so Important in Social Work with Children?

Lotta Berg Eklundh

Lotta Berg Eklundh is a social worker and holds a Licentiate degree in Social Work. She has worked as a researcher at the Research and Development Unit Nordost in Stockholm County and, in parallel, as a teacher and supervisor in social work at the Schools of Social Work at Stockholm University, Uppsala University, and Södertörn University. She has extensive experience of social work focusing on children, young people and families, children's participation in investigative work, and above all the importance of how feedback can be given to the child.

Summary

Children under the age of 18 whose parents have substance abuse issues, mental health problems, or issues involving violence are often subject to investigations and interventions within the social services. Both the Swedish Social Services Act and the UN Convention on the Rights of the Child emphasise the importance of children's participation—especially for children identified as next of kin due to parental problems. The issue of children's participation has been a central theme in the author's work as a research leader at a Research and Development unit, as a university lecturer, and in her own research.

Several studies conducted at RD Northeast (FoU Nordost) in the Stockholm region have aimed to examine how social services work with children's participation. One of the most frequently cited was conducted in seven municipalities and compared children's participation before and after the implementation of BBIC (Children's Needs in Focus). The study found that children's participation had increased since the introduction of BBIC. However, the participation primarily involved acting as informants during the investigation phase. Feedback to the children was rarely provided, which was also highlighted in a study on adult children's experiences of contact families.

Another study on research circles within social services and children's participation involved the author as research leader. This two-year development project, based in a municipality in the Stockholm region, focused specifically on how social services handle children's participation and the presence or absence of feedback to the children.

This chapter discusses how children, especially children as next of kin, can be involved in social services' work throughout investigation, intervention, and follow-up. It also highlights the importance of providing feedback to children regarding how their participation was considered during assessments, decisions, interventions, and case closure.

35. Children as Next of Kin in Social Services and Palliative Care for Adults – From Words to Action

Ulla Beijer

Ulla Beijer holds a PhD in Medicine and is a social worker. She has extensive experience as both staff member and manager within different areas of social services and has conducted research at the City of Stockholm's Research and Development Unit, the STAD competence centre in Stockholm, FoU Sörmland, Karolinska Institutet, the Institute of Public Health Sciences, and the Departments of Women's and Children's Health and Clinical Neuroscience. Her research has addressed mortality and morbidity among homeless men and women, men's violence against women with substance use problems, children of homeless women with substance use problems, and outreach work.

Summary

This chapter presents three studies on children and young people as next of kin in social services and in palliative care for adults.

The first study comprises research circles for social workers in child and youth care that were carried out in the counties of Sörmland, Skåne, Östergötland and Northeastern Stockholm. In total, nearly 100 social workers participated. These circles focused on reviewing their own practices regarding the participation of children and young people, they also included interviews with children and young people who had been involved in social service cases. The evaluation showed that research circles are an important method for increasing social workers' knowledge, awareness, and competence regarding the participation of children and young

people in child and youth welfare services. It also revealed certain obstacles that hinder such participation within social services.

The second study describes a support conversation model for parents of young children (0–6 years old), where one parent has substance abuse issues. The model, developed collaboratively by researchers and social workers within a social service context, consists of a series of structured conversations involving both parents. The parents may live together, be separated, or even reside in different locations. The model is based on three pillars: (1) children's needs and rights, (2) parental responsibility, and (3) societal ambitions. The focus of the conversations is the child, not the parents' relationship or the addiction problem itself. The pilot study showed that the model reached relatively young couples who otherwise would not have had the opportunity to discuss how best to protect and support their child's development. All participants responded positively and reported improved cooperation as parents. A surprising result was that several fathers with substance abuse issues, initiated outpatient treatment on their own during the course of the conversations.

The third study focuses on children as next of kin in palliative care for adults. Over the course of a year, palliative care professionals in one region developed action plans for children as next of kin. An evaluation showed only small changes among healthcare staff in terms of awareness of children and young people as next of kin and their opportunities to be seen and supported by professionals.

36. Me & My Family – A Family Intervention with the Child in Focus

Kari Jess, Ann Lyrberg

Kari Jess holds a PhD in Social Work and currently works as Senior Lecturer in Social Work at Dalarna University. Her research has mainly focused on substance misuse and children. Developing social work in close collaboration with practice is a particular interest.

Ann Lyrberg is a social worker and doctoral student in Social Work at the Faculty of Health and Occupational Studies, University of Gävle. She also works as an analyst at the Research and Development Unit Welfare, Region Gävleborg. Her doctoral

work concerns children growing up in families where adults have harmful use and addiction, and children's participation.

Summary

The family intervention *Me & My Family* was developed based on previous research indicating a lack of outpatient services targeting entire families affected by at least one parent's problematic alcohol or drug use. The intervention, delivered in collaboration between child and family services and adult services, engages the whole family in eight manual-based sessions and two follow-up meetings. The explicit goals of the intervention are to strengthen children's rights and perspectives through communication, with a particular focus on their need for information and support.

Research on the intervention has shown that *Me & My Family* empowers children, alleviating feelings of guilt and shame. An outcome study demonstrated that the intervention contributed to increased family closeness, reduced chaos in the household, and decreased behavioral problems in children. Additionally, parents reported reduced symptoms of anxiety and depression, as well as decreased alcohol and drug consumption, although the latter was not an explicit goal of the intervention.

The implementation of the intervention in the study followed a detailed plan that included training in the program's content and theoretical foundation, supervision, booster sessions, and specific research responsibilities for facilitators. Evaluation of the implementation underscored the importance of providing time for reflection and managerial support.

37. The Family Model: A Family-Focused Approach to Child and Adult Psychiatry

Camilla Linderborg, Margareta Östman

Camilla Linderborg is a social worker and doctoral student at the University of South-Eastern Norway, Faculty of Health and Social Sciences, with a focus on practice-near research and child and adolescent mental health in a broader perspective. She works in child and adolescent psychiatry in Region Stockholm as a counsellor and unit manager. Her doctoral project focuses on the practice development project The Family Model.

Margareta Östman is a social worker and Professor Emerita in Health and Society. Her clinical experience comes from many years as a social worker in municipal social services and as a counsellor in healthcare, both somatic and psychiatric care, where she has held both therapeutic and managerial roles. Her research interest focuses on how mental ill health in one or more family members affects the whole family and the situation of underage children, as well as interventions for managing these situations.

Summary

Family members of children and young people with mental illness must adapt to many different factors and treatment efforts, which can often be demanding and contribute to a worsening of the situation in the family. The burden of maintaining continuity across services frequently falls on the family, creating a complex and sometimes confusing situation for both families and professionals. While mental health professionals express a strong desire to support the broader family system, they often find it difficult to implement such efforts within the constraints of their existing roles.

The chapter presents The Family Model, a development project currently operational in child and adult psychiatry services in the Stockholm region of Sweden. It is a program that aims to strengthen a child and parent perspective on treating mental illness. A further aim is to enhance inter-agency coordination between child and adult psychiatric services. To date, over 500 families have participated in interventions delivered through this model.

Initial findings indicate that more than half of all patients in child psychiatry and a third of patients in adult psychiatry have at least one family member with a concomitant mental illness. Most therapists we surveyed acknowledged the

importance of considering the mental health status of other family members in their regular treatment work. However, although those therapists were aware of the complex situation in which these families live, they were not always able to provide family-oriented interventions within the context of their present practice.

Following the introduction of The Family Model, therapists reported they found it both user-friendly and flexible. Families expressed great trust in the model, appreciating its comprehensive perspective that considers the needs and strengths of the entire family unit. They felt that it helped accelerate the path toward improvement and recovery.

Both therapists and the family members felt that by promoting a dialogue within families, and between families and psychiatric services, the model enhanced a family's ability to handle their situation. Therapists concluded that The Family Model was beneficial in their clinical work and increased coordination between participating agencies. Both therapists and family members found The Family Model advantageous as a treatment option in both child and adult psychiatry.

In conclusion, our analysis presents recommendations for mental health providers who wish to introduce a more family-oriented way of treatment provision.

38. Young Carers in Finland

Tiina Sihto, Susanna Haverinen, Sini Järnström

Tiina Sihto is a Docent of Social Policy, specialising in care research. She works as an Academy Research Fellow at the University of Eastern Finland within the project *Young Carers in Finland*. In her research, she is particularly interested in the difficult and often hidden experiences of care.

Susanna Haverinen is a doctoral student at the University of Eastern Finland within the project *Young Carers in Finland*. She studied young carers already in her Master's thesis and is now continuing with the topic in her doctoral work. In addition to young carers, care policy and welfare state research are areas close to her heart.

Sini Järnström is a sociologist and works in the *Young Carers in Finland* project at the University of Eastern Finland, where she is writing her doctoral thesis on transitions in young carers' life courses, their family networks, and their experiences of meeting needs for help and support.

Summary

This chapter explores the current situation of young carers in Finland. The starting point of our chapter is a question that we, as researchers focusing on young carers, have been pondering: Why is Finland falling so far behind Sweden when it comes to recognising and supporting children as next of kin and young carers?

We understand that a part of the explanation lies in the differences between the Finnish and Swedish welfare state models, as well as in the ongoing crisis within Finland's social and healthcare sectors.

However, despite Finland lagging behind when it comes to recognition and support for young carers, substantial progress has been made out over the past decade. In this chapter, we present current development and research initiatives related to young carers in Finland and reflect on the steps needed moving forward.

We conclude that it is essential to continue raising awareness about young carers among young people themselves, professionals working with youth (e.g., teachers, social and healthcare professionals), and political decision-makers. Equally important is the development and clarification of appropriate terminology in Finnish to describe the phenomenon.

Currently, Finland lacks sufficient resources for work related to young carers. Therefore, gaining support from both local and national governmental actors and organisations is vital. Our longer-term goal is that, following adequate awareness-raising and lobbying efforts, Finland will establish comprehensive and nationwide services and support systems for young carers.

39. “We’re in the Same Boat. Nice. We’re in the Same Boat. Unfortunately.” – A Story About a Support Group for Young Adults Growing Up with Mental Illness in the Family

Kjell Andersson, Vibeke Loga, Lisa Gustafsson

Kjell Andersson is trained as a youth recreation leader, has training as a support group leader, and is also an artist. He has worked with people for 50 years, initially in recreation and schools. Since 2010, he has worked at Gyllingen, Stiftelsen Gyllenkroken, Gothenburg, as a support group leader for children and young people who are next of kin to an adult with mental ill health.

Vibeke Loga trained in Norway with a specialisation in social pedagogy and later completed further education in social work at the University of Gothenburg. She has many years of experience in addiction care and as a group leader in relapse prevention. She has support group leader training and works at Gyllingen, Stiftelsen Gyllenkroken, Gothenburg.

Lisa Gustafsson is trained as a social educator and holds a Master of Arts degree in Social Work, as well as training as a support group leader. She has extensive experience of support group activities, including with Junis, the Church of Sweden, and Gyllingen, Stiftelsen Gyllenkroken in Gothenburg.

Summary

Gyllingen in Gothenburg offers various forms of support with a focus on children and young people who have someone in their family with mental health problems. This chapter focuses on a support group for young adults aged 15 to 25, where participants come together to share experiences, cope with their circumstances, and strengthen their mental well-being. It describes the first year of the group – from concept to implementation.

Based on prior experience, Gyllingen recognised that young adults often find it difficult to commit to regular group sessions. A more flexible drop-in model proved to be successful. The group was co-developed with participants, and structure and routines were established jointly. Meetings are informal and characterised by open, free-flowing conversations covering both light and difficult topics. Participants support each other, and by sharing their stories, they create a sense of connection

and mutual understanding. Some need time before feeling ready to talk about painful issues, and it's essential to let each individual set their own pace.

The group leaders work to create a safe and validating environment where young people can be themselves. Leading such a group requires professional training, experience, and personal aptitude, along with access to supervision and opportunities for reflection. A foundational method used in the group is trauma-informed care, which emphasises safety, relationships, and coping strategies.

The group provides a sense of community where participants both give and receive support. The combination of lived experience and professional expertise creates valuable therapeutic effects.

The chapter presents experiences from the meetings with young adults, interpreted from the perspective of the group leaders. The title of the chapter comes from one of the participants and reflects the duality of the group, where the conversations concern both joy and seriousness in a strong community.

40. Are Support Groups a Good Way to Help Children as Next of Kin?

Annemi Skerfving

Annemi Skerfving is a social worker and holds a PhD in Social Work. For many years, she worked as a teacher and researcher at Stockholm University, focusing on children in social work. She has, among other things, conducted several evaluation studies of support group activities at the Research and Development Unit, Region Uppsala, and at the Centre for Psychiatry Research, Region Stockholm.

Summary

Children in families affected by an adult member's severe problems often live in difficult circumstances and are in the need of support. The CAP-program, based on the idea that "children are people too", was originally designed by Alcoholics Anonymous, AA. The aim of the group intervention is to increase the children's knowledge about the adult's problems, help them find useful coping strategies,

reduce feelings of stigma, and improve their sense of coherence and resilience. The CAP-program has been used in Sweden for a long time. It has been adapted to various parental problems, though the core perspective remains unchanged. The groups are manual based, but structure and content can vary, from strict adherence to a flexible design influenced by the participants. Studies show that children attending the groups generally bear a heavier psychological burden than their peers. The interventions generally help reduce these burdens and alleviate problems. Generally emotional problems are more typical for girls while behavioural issues are more prevalent amongst boys. Most participants state that their quality of life has improved following the intervention. However, the most vulnerable children often drop out early and may not receive the support they need. Despite this, participation may still offer children a sense of being seen and heard, and an opportunity to reflect on their situation in a new way.

A common challenge is reaching children in need. Only around one percent of children who would benefit from support groups participate in them, with boys being especially difficult to engage. Barriers may include shame, stigma, fear of revealing family issues, geographic distances, or professionals' lack of knowledge regarding the intervention. Providing clear information and helping to overcome practical obstacles can make participation easier. Web-based support groups could increase accessibility and reduce stigma.

Involving children in shaping the intervention may help engage more boys. Parental involvement through parallel support groups has also proven to be effective in encouraging children's participation, adding valuable knowledge for both parties, and improving family communication.

Support groups are a valuable, though not always sufficient, intervention for children as next of kin. They may be enhanced or complemented by additional support for parents or entire families.

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From the anthology

Children are Next of Kin – Do We Dare Listen to Them?

Nka Children as Next of Kin 2025:2 - Extract

All children are next of kin, and their role as next of kin shapes their lives from the very beginning through the transition to adulthood and into adult life. Swedish legislation, including the Health and Medical Services Act and the Social Services Act, as well as the UN Convention on the Rights of the Child, highlights the need for support for these children. Difficulties affecting parents, siblings, and other caregivers also affect the children themselves.

Linnaeus University and the Swedish Family Care Competence Centre (Nka) have been commissioned by the National Board of Health and Welfare to compile and disseminate knowledge in the field of children as next of kin. As part of this assignment, a second anthology on children as next of kin has been published. This anthology demonstrates the extensive development of knowledge, methods, and tools for supporting children as next of kin that has taken place since the first anthology was published in 2015.

The anthology is intended for politicians, policymakers, and service developers; professionals who encounter children as next of kin and their parents; students in nursing, medical, social work, and teacher education programmes, as well as other relevant professional training programmes. It also aims to reach non-profit organisations and individuals seeking knowledge about the living conditions of children as next of kin and young carers.

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Swedish Family Care Competence Centre
Box 601, 391 27 Kalmar
Tel: 010-358 30 20
Email: info@anhoriga.se
www.anhoriga.se