



Summary of chapters  
**TO SEE CHILDREN AS  
NEXT OF KIN**

- relationships, interventions  
and care responsibility

För svensk version vänd

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relationships, interventions and care responsibility”

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## Summary of chapters

### TO SEE CHILDREN AS NEXT OF KIN - relationships, interventions and care responsibility

Children are born as next of kin and grow up as next of kin to parents and siblings and other significant persons in the family. Young children have their foundations of security and trust in these relationships on which to build their lives. Conversely, the difficulties affecting the parents or siblings have consequences also for the children. What are these consequences and how can we understand children's caring? What roles might the child have in his or her family? When do children and parents need support and how?

In this anthology, researchers who participate in or who are invited to the Swedish research network "Children as next of kin," attempt to explore, describe and explain the meaning of children as next of kin based on current research. Different themes are raised, such as, children's positions in the family where vulnerability and dependency are described in the relationships to the parents, and the children's active behavior is highlighted in relation to the parents and siblings. One such example is when children become care-givers for siblings or parents, which is also described in an international outlook. Furthermore, how many children as next of kin are covered in the context of the Healthcare Act is reported and how they do in school. One chapter concerns the current knowledge on existing interventions for support to children and parents. Support to next of kin siblings and research on violence in the family are also highlighted.

The book is intended for students in nursing, medicine, social work and teaching training programmes, as well as in the professional education of staff who meet next of kin children and their parents in need of support. This book is also meant for policy makers, managers and developers, private persons and non-profit organizations seeking knowledge about the living conditions of children as next of kin.



## Children as next of kin

### 1. To see children as next of kin -

*Elisabet Näsman, Karin Alexanderson, Stina Fernqvist & Johanna Kihlgård*

To speak of young children as next of kin is a relatively new way in social work of denoting a child's position in the family. What are the consequences of such a perspective? What is brought to light and what is obscured from view? In this chapter we discuss the concept "children as next of kin" in order to contribute to greater understanding about what the concept might mean and what the consequences may be for children when a carer perspective is used. Based on childhood sociology, we problematize the view of children as next of kin. Children are placed in a social position as next of kin within an institutional and professional context, at the same time as their position as child is characterized by society's overarching age power structure. The chapter focuses on children as next of kin to parents with problems. What is the interaction when they might be vulnerable, have their own problems, be recipients of society's services, but also be actors? Children can take on the responsibility of caring in the family for siblings, parents and themselves. Here are political/ ideological and professional dilemmas, partly because different concepts are used for children as next of kin, and partly because different perspectives exist among the institutional contexts where children are actualized as next of kin. This appears for instance in current documents from the National (Swedish) Board of Health and Welfare.

### 2. Children as next of kin – in the shadow of parents with problems

*Gunvor Andersson*

This chapter is based on social child care. Not all children with problems come in contact with social services, but when they do receive assistance from social child care, they commonly have parents whose lives are disrupted by substance abuse, mental illness or intellectual disability. This chapter covers these subjects: 1) It can be a dilemma to see the child both as an individual and as a dependent of his or her family, especially when there is a conflict between the child's and the parents' needs, interests and rights. 2) The parent's gender and type of problem influence the professionals' initial response and preparedness with treatment. This may apply to health care readiness to report concerns that the child is at risk, or the social services' considerations in an investigation. 3) Studies that communicate the child's own voice as "next of kin" show similarities in how their lives are affected and how insecurity is experienced. They often lack information that can make the parents' behaviour understandable and manageable. 4) The concept "child" includes ages 0 to 18, which requires a span of professional treat-

ment and knowledge of child development. 5) When the family is seen in context, differences in vulnerability appear based on, e.g., family composition, social and economic status, and ethnic background. The combination of risk factors inside and outside the family increases the risk of the child's vulnerability, particularly if there are no corresponding protective factors. 6) The chapter concludes with reflections on untapped skills and remaining knowledge gaps. We know more than we do. We know the importance of providing information to children about their parents' substance abuse problems, mental illness and neuro-psychiatric problems, and functional disabilities. We know the importance of ensuring the child has access to an adult who will hear, take the time to listen and care about the child's situation, or who can offer a secure relationship when security in the family is failing. There are knowledge gaps, such as about younger children's experiences and position as next of kin and about everyday life at home, in preschool/school and in the after-school programme.

### 3 To regard children as next of kin in social services – example of the contact family

*Lotta Berg Eklundh*

Contact families are one of the most common initiatives by the Swedish social services in their work with children and families; it is a voluntary support measure offered to families according to the Social Services Act. Contact families are “laymen,” people who offer the child an alternative family with regular contact. The children stay there one or a few weekends a month and sometimes also on holidays and participate in the contact family's activities. Besides support and relief for the parents, and stimulation and access to other activities for the children, the contact family's assistance should contribute to strengthening the social network of both children and parents. One of the most common reasons for applying for a contact family is that the contact family assistance is a relief for the parents. A majority of the children with a contact family have parents with substance abuse or psychological problems. Because the effort is directed toward the children, but recognizes the connection with the parents' social problems, this chapter argues that a carer perspective of the children should entail a change in the social service work with and for the children. A previously conducted longitudinal study of 50 children with contact families and an interview study with eight young adults (ages 18 to 30 years) form the basis for the analysis and discussion of the carer perspective. Both the children in the first study and the young adults in the second study state they got the impression that they had a contact family because their parents needed support and relief. The majority had not felt they participated in the process, but instead perceived it as the parents and social services having decided on the assistance without listening to them. Half of the young adults described a close relationship with his or her contact family, and the contact mammas were a support in becoming an adult.

## How many children are there and how are they doing?

### 4 Why didn't anyone see me: about the unwillingness to notice the uncomfortable

*Mikaela Starke*

This chapter, “Why didn't anyone see me: about the unwillingness to notice the uncomfortable,” aims to describe childhood, upbringing and caring to parents with intellectual disabilities. It is based on interviews conducted with two young adults with focus on their upbringing, family circumstances and meetings with professionals. The interviews reveal that the young adults' upbringing conditions are very different, but in their stories there are a variety of common factors, such as they both sought attention from their surroundings. Above all their stories revolve around how they tried to get attention from professionals whom they met in their daily lives, but also from other adults like their friends' parents. The young adults ask themselves, how could it be possible that they as children and their living circumstances did not get the attention they needed? The young adults interpret the absence of interest as an unwillingness to notice something uncomfortable. Based on the young people's accounts, one can conclude that much could have been done differently. One step in the change process is to increase knowledge among professionals who come in contact with children and parents by spreading current research and its practical consequences. In addition to this, the competence of professionals must be secured so that decisions concerning adequate knowledge-based assistance can be made, and professionals should actively work for compliance with the United Nations Convention on the Rights of the Child and the United Nations Convention on Rights of Persons with Disabilities, so that both the child's and the parents' voices are considered. Finally, there must be awareness of this discourse in order to discuss and reveal the children and their parents. Only then can this taboo-laden area be uncovered.

### 5 Children as next of kin in care – how many are they?

*Anders Hjern, Helio Adelino Manhica*

This chapter is based upon the first report in the series, Children as Next of Kin, which is a part of the implementation of new legislation that strengthens children's rights as next of kin. The task is conducted by the Centre for Health Equity Studies (CHESS) and Karolinska Institutet/ Stockholm University on behalf of the Swedish Family Care Competence Center and the National (Swedish) Board of Health and Welfare. The purpose of this report is to estimate the extent of the groups of children affected by the new legislation. The results of the survey are

presented in this chapter in summary form and concluded with a discussion of the results and the needs that emerged. Nearly eight percent of children born in Sweden during 1987-89 had experienced before their eighteenth birthday that at least one parent had been admitted to the hospital due to mental illness and/or addiction to alcohol or drugs during childhood. Significantly more parents indicated problems with alcohol and drugs to a milder degree. In total nearly one child in thirty had at least one parent who passed away before the child's eighteenth birthday, which corresponds to 3,500 children per year. Abuse, illness and death of parents affect primarily children who find themselves in a vulnerable social position in the Swedish society. A complete review is found in the report, Children as next of kin to patients in care – how many are they? (Hjern & Manhica 2013).

## 6 Children as next of kin – how is it going in school?

*Anders Hjern, Lisa Berg, Mikael Rostila, Bo Vinnerljung*

This chapter is based upon Report 2 in the series, Children as Next of Kin, which is a part of the implementation of new legislation that strengthens children's rights as next of kin (Hjern & Manhica 2013). The task is conducted by the Centre for Health Equity Studies (CHESS) on behalf of the Swedish Family Care Competence Center and the National (Swedish) Board of Health and Welfare. The chapter describes the school performance in Grade 9 for a group of children who are next of kin and who experienced at least one parent receiving care in the hospital for substance abuse, mental or physical illness, or died before the child left compulsory school. The results from this study show that the parents' substance abuse, illness and death rarely did not affect their children's school results in a negative way. Professional teams who meet these children should therefore consider that assistance with schoolwork and homework could be an important component of psycho-social support. The study also points to the particularly poor school performance among children where the parents' illness or death affects families who have contact with social services, either in the form of income support or through the child being placed in social care. The poor school performance of these children makes social services a natural platform for interventions with the aim of supporting schoolwork for children in families with social vulnerability, including illness and death of a parent.

## 7 Children who lose a parent: Consequences for health and mortality

*Mikael Rostila*

The purpose of this chapter is to give an overview of the health consequences of losing a parent. The chapter addresses possible explanatory factors for why children's health is negatively affected by this event, such as increased acute and chronic stress as a consequence of the incident, changes in health behaviours, reduced mental well-being, poor care from the remaining parent, and loss of connection related to the death. The chapter also discusses how factors such as the parent's cause of death and the gender can possibly be of influence. The chapter then takes up the results from an earlier research study that investigated how the loss of a parent affects mortality among minors (ages 10 to 19 years) and young adult children (ages 20-29 years), showing that the loss of a parent primarily has consequences for minors (ages 10 to 19 years) and that the loss of a mother affects minor-aged children most. To lose a mother through an unnatural cause of death, such as an accident, suicide or murder, had the greatest impact on child mortality risk. The results showed also that the loss of a mother primarily had implications for girls' mortality during the first year after the parent's death, while there were consequences both short and long-term among boys (up to 9 years after the loss). Minor-aged children therefore constitute a special risk group, especially those who have lost a mother. Health care and other agencies that come in contact with children affected by grief should therefore pay greater attention to the negative consequences. In order to create effective measures regarding supporting grieving children, it is nonetheless important to continue to investigate both explanatory factors and specific diseases and forms of ill-health that a parent's death can lead to.

## 8 Children's need for information, advice and support when a parent receives adult psychiatric care – how is the law complied with in everyday clinical practice?

*Gisela Priebe & Maria Afzelius*

Extensive research indicates that a parent's mental ill-health may constitute a risk factor for children's psychological development and health, especially when the mental ill-health makes it hard for the parent to function fully as a parent. Since 2010 there is an addition to the (Swedish) Health Care Act in that care should take into account the children's need for information, advice and support, and there are currently a number of actions to choose from. We conducted a study to investigate compliance with the law in adult psychiatry, with Psychiatry Scania as an example. Within Psychiatry Scania, since 2010 guidelines exist on how to work taking into consideration the needs of children. It prescribes recording in

a patient database the children and the assistance for the children and their parents. Our study indicates that there is significant under-reporting of the patients' children, and for only a minority of the registered children or their parents is there recorded any assistance or interaction with social services or the children's and teenager's psychiatrist. Within the scope of this study interviews were also conducted with key persons within adult psychiatry who demonstrate that implementation of the legislation is a complex process. Similar difficulties have been found in other countries, such as Norway and Australia. Based on the study results, we recommend strengthening the children and family competence within adult psychiatry that traditionally focuses on the adult patient, create a model for when certain interventions should be provided to certain families, and clarify, simplify and follow up the record-keeping in the patient database.

## Interventions

### 9 Support for children whose parent has a serious physical illness

*Ulrika Järkestig Berggren & Elizabeth Hanson*

Children who live in a family where one parent suffers from a serious physical illness have their life circumstances changed in many ways. This chapter presents research on how children may experience their situation when a parent becomes seriously sick, in regards to both difficulties and more positive experiences. Children's possibilities to develop relevant protective factors are also discussed in this context. Protective factors and risk factors can be linked to family relationships, the parent's disease condition, external circumstances and the child's personal characteristics. Also, results are presented from a knowledge overview of methods for providing children and parents support when one parent has a serious physical illness. The knowledge overview shows eight methods reported in eleven studies. The methods focus on information given to children, group support and parental support, and for families with multiple risk factors, a long-term support directed to both children and parents. Existing methods are directed primarily to families where one parent suffers from cancer or HIV, that is, a condition that is potentially life-threatening. Most methods indicate that children's fears decrease. The knowledge overview also shows that methods are lacking for supporting a family living with an illness or functional disability during the child's entire childhood. Implications for research and professional practice deal with developing such methods or programmes, and using assessment measures that recognize changes in the children's social situation, such as responsibilities in the home, school performance and participation in after-school activities.

## 10 Support for children when one parent dies

*Ann-Sofie Bergman & Elizabeth Hanson*

To lose a parent in death is highly stressful for children during childhood. When a parent dies, it means a crisis and radical change. The loss has enormous implications, as it involves losing a person who stands for love, security and daily care. Predictability and stability in life are adversely affected. The loss of one or both parents is linked to greater exposure and vulnerability for children. The chapter discusses consequences for children when a parent dies, risk factors and protective factors for the children, current state of research on the effects of support interventions directed to children, and research about children's perceptions of their own needs and of what has been supportive for them after their loss. The evaluated interventions are based upon different forms of support to children and parents, such as support groups and camps for children, family support and parental support. The research review of effects of support indicate that support interventions can prevent children from developing serious problems after the loss of a parent. Based on the current state of knowledge, there is support that interventions for children whose parent dies should be directed to both the child and to the child's remaining parent/ care-giver. Support for remaining parents can improve their own health and promote their parenting ability, so that they can give better support to their children. At the same time support needs to target the children directly. Furthermore, the common support to the children and parents with focus on family interaction and family communication has shown to give positive effects. Qualitative studies show that the children have appreciated participation in support interventions where they have helped them to see that they are not alone in their situation. Furthermore, children describe that it has been helpful for them to get to express their emotions, grief, loss, to feel understood, to acquire knowledge and understanding, and also to get to do fun things/ activities despite the grief.

## 11 Children in families with alcohol problems – can a web-based programme help teenagers?

*Tobias Elgán, Helena Hansson, Nicklas Kartengren & Ulla Zetterlind*

Investigations conducted both in Sweden and in other countries show that a large proportion of children and teenagers grow up in families with alcohol problems. Growing up under such family circumstances can carry a variety of physical, psychological and social problems as well as an increased risk of early onset of alcohol use and one's own substance-dependency problems. Therefore there is a need to offer different types of assistance to this group of children and teenagers in order to prevent future problems. This chapter describes a new web-based

self-help programme, Alcohol and Coping, which is directed to teenagers with parents who have alcohol problems. The programme is currently being evaluated but some preliminary results are presented and discussed.

## 12 Support groups for children and adolescents placed in foster homes

*Ulla Forinder, Yvonne Sjöblom & Agneta Rönn*

In this chapter we call attention to the group of children in foster homes and young adults in public social care who are next of kin to parents with psycho-social problems. We write about these children's living conditions and particular relationships during upbringing. We describe also an ongoing intervention with support groups for this group of children and young adults, and the model for the intervention and the underlying theoretical assumptions upon which the intervention is based. The Family House in Helsingborg, the context conducting this operation, is also briefly presented. The chapter concludes with a description of how the intervention is evaluated and a discussion of the opportunities and limitations with this type of intervention for children growing up in foster homes.

## 13 Beardslee's family intervention – a health-promoting intervention for children in risk environments

*Anita Cederström & Heljä Pihkala*

The purpose of this chapter is to describe Beardslee's family intervention, a health-promoting method for children in identified risk groups which ultimately aims to be preventative. We describe the procedures of the method, its theoretical foundations, what the method aims to achieve, current state of research on the method, plus a case study of one intervention where the parents have a drug problem. The method has been developed by American child psychiatrist and professor, Bill Beardslee and his colleagues, in order to provide support to children with parents who have depression or bi-polar syndrome. The collected research to-date has with a few exceptions only dealt with interventions with parents who have had mental ill-health. The results of the research show that the method achieves what it aims to, and that it does not cause any harm. The example of the case study shows that the method design itself is possible to use with risk groups other than where parents have a mental ill-health. This is because the purpose of the method is to increase communication in the family about the parent's illness / substance abuse/ problem based on the children's questions and needs, strengthening the parenting function and making the parents aware of protective factors and how they can strengthen these in their children, plus bring out the perspective of the different family members, primarily that of the children. That which needs to be changed in the intervention according to the actual risk group is the psycho-educative part concerning the parent's situation.

## 14 To be a sibling close to a child with cancer

*Margaretha Jenholt Nolbris*

Every year 300 children are diagnosed with cancer in Sweden. Cancer is life-threatening and means that all family members are affected on a daily basis. Interviews with 78 siblings, ages 8 to 36 years, to a child with cancer describe their experiences. Siblings are unprepared for their brother or sister to be diagnosed with cancer. Many thoughts, feelings and questions are aroused about what everything will be like. It is important that the close sibling then understands what is happening in order to be able to manage his or her own new situation. Siblings must have consideration for the child with cancer, and they can feel neglected by parents, staff and other adults. This means that siblings are alone physically and also alone with their thoughts and feelings. The parents cannot always cope with parenting, and the siblings may take on the role of being parent and also being the care-giver of the sick brother or sister. Much sadness is experienced also by siblings. The first sorrow is experienced immediately after the cancer diagnosis is communicated to the family. The next sorrow is that the sibling thinks the cancer child has lost a normal life and childhood. The third instance of sadness is the sense that they feel neglected. The fourth is the grief that occurs if the sick child dies. Early support interventions for siblings are needed by keeping the siblings involved and continually informed, not forgotten, and that they be asked about their thoughts and feelings. Children say it is important to meet other siblings in the same situation and share experiences. Another way to help is for the sibling to be able to meet the sibling-supporter available in all pediatric oncology centers. It is also important to get information about the disease, which can be given with the help of pictures to be able to talk about feelings and thoughts. For younger children, play can be used and for older children, SMS and Internet can be tools in addition to personal conversations to provide support.

## Violence in families

### 15 Children forced to grow up with violence between their care-givers

*Karin Grip & Ulf Axberg*

Too many children are forced to live with violence between their care-givers, or violence from one care-giver toward the other. When one asks Swedish children themselves, circa 10% volunteer they have experience of having witnessed violence between their care-givers. The negative consequences both short and long-term that violence in close relationships has, are well documented in both national and international research. Common adverse consequences involve affecting cognitive functioning such as memory and ability to plan, somatic illnesses such as increased allergies and asthma, and mental ill-health. Inward symptoms such

as depression, anxiety and post-traumatic stress, as well as outward symptoms such as behaviour problems, are also common. Children who have grown up with violence between their care-givers also run as a group a greater risk of both becoming a victim of violence in their own close relationships or of subjecting their partner to violence when they begin to have close relationships in adolescence or early adulthood. Overall findings point to the importance of developing and using methods that can provide support to assessing if children are vulnerable, and in which case, how and to what extent, and the possible need for protection. Furthermore, the assumption is also that assistance can be offered to the child on various levels based upon need.

## 16 Childhood experiences of violence and conflict between parents – young adults' experiences and health

*Åsa Källström Cater*

This chapter is about children as next of kin to parents who practiced and exposed themselves to violence and conflict in their relationship as a couple. The purpose is to highlight the children's perspective of their experiences and the meaning of these experiences, against a background of current Swedish research. The chapter presents some results from a recent research study: the RESUMÈ-study (Retrospective study of young people's experiences). In the RESUMÈ-study, a random sample of 2,500 young adults ages 20 to 24 years old, in Sweden, answered questions about their experiences of violence and conflict during their upbringing and how they are feeling as adults. The results presented in the chapter give a more nuanced picture of childhood experiences regarding parental violence and conflict in Sweden, generating questions such as how violence and children's exposure and witness to violence should be defined, and how women's reporting of having experienced violence to a greater extent and more often, should be interpreted. Although we found a significant risk for psychological problems as an adult, linked to childhood exposure to parental violence and conflict, most of the respondents were spared such suffering as adults. Also, particularly for women, the childhood experiences of violence and conflict between parents were associated with ill-health in adulthood. Given the background of a widespread view among the participants, who did not disclose their experiences, that still nothing can be done about such violence, the chapter also raises issues concerning society's possibilities to prevent violence and the need to develop protection for young people.

## Young carers

### 17 Children as next of kin, victims and care-givers – two types of examples

*Karin Alexanderson, Stina Fernqvist & Elisabet Näsman*

How has earlier research viewed children who at the same time are next of kin, victims and care-givers? In order to discuss this and establish some dividing lines, this study reviews two family situations which differed from each other with respect to the parents' identified problem area, substance abuse and cognitive difficulties, respectively. The purpose of discussing so widely diverse situations is to shed light on the complexity in how researchers approach the issue of children as next of kin, when they are simultaneously victims and actors in families where adults have problems. What are the similarities and differences in the picture the research provides of these two types of examples? How does the research describe the children and their position in such families? What is highlighted as essential in order to catch the children's situation? Where does the child's potential vulnerability lie and to what extent are the children considered actors in their own life and may then have responsibility for providing care for siblings, parents or themselves? How is this interpreted in relation to the child and parent positions? Our analysis is based on a childhood sociological perspective with the perspective's critical review of the age power structure in society and revealing the child as actor. The article highlights significant differences in the research perspectives in the two types of situations, but primarily shows the common focus which lies on the adults. A conclusion is therefore that more research is needed that emphasizes the children's own voices about their situation, vulnerability and care in the family with the variation that may be in different next of kin conditions depending on which problem the parents have.

### 18 Perception of the concept “young carers” and the policy response: a transnational perspective

*Saul Becker*

This chapter is based on British research on “young carers” and presents a definition of the concept. Research on young carers is presented from a number of countries with the purpose of developing the concept and understanding of “young carers” and the tasks they take responsibility for. The analysis leads to a classification of how different countries meet young carers' needs and identifies some key factors that influence the policy response. The chapter discusses the need for further research and social-political consciousness, as well as measures to help children who for different reasons may take major responsibility in caring for their parents or siblings.



The full anthology, and each individual chapter can be downloaded at [www.anhoriga.se/publicerat](http://www.anhoriga.se/publicerat)  
Only currently available in Swedish (see English overall summary and individual chapter summaries)

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