



## Children as next of kin in Sweden

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## Foreword

This overview, ‘Children as next of kin in Sweden’ is a summary of eight reports on children as next of kin in Sweden. The government initiated a wide spreading development work, in which the National Board of Health and Welfare, the National Institute of Public Health, Swedish municipalities and health care regions collaborated to strengthen support to children and young people in families with substance abuse, serious illness or mental ill-health, violence or death of a parent. These eight reports provide the foundation for this work. The references to the original reports are found at the end of the overview. The overview builds on the results from the studies:

Children as next of kin-how many are they?

Children as next of kin and school performance

Health and social living conditions in young adults with childhood experience of parental death

Health and social living conditions in young adults with childhood experience of parental substance abuse and mental illness

How many children in Sweden experience parental cancer and what are the consequences from a life course perspective?

Traumatic stress in refugee parents and consequences for their children – a systematic literature review

The societal cost of children who have grown up with parents with mental illness, addiction to alcohol or drugs

The societal cost of fetal alcohol syndrome (FAS) in Sweden

The reports are produced by researchers at CHESS, Karolinska Institute/University of Stockholm, The Swedish Family Care Competence Centre (Nka) and Linnaeus University (LNU). The work was commissioned by Nka/LNU who in turn had a remit from the National Board of Health & Welfare to build up a knowledge base and to disseminate the knowledge and enable knowledge exchange and learning networks to take place.

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## Children as next of kin in Sweden

The first report in this series aims to provide a general picture of the number of children in Sweden affected by a parent's mental or physical illness, substance abuse, and death. The report is primarily based on analyses of anonymized data on inpatient care from the Swedish Hospital Discharge Register during the period 1987–2008 and deaths in the Swedish national Cause of Death Register between 1973–2008. Register data from Statistics Sweden was used to link parents to their biological children and to define the social characteristics of the families.

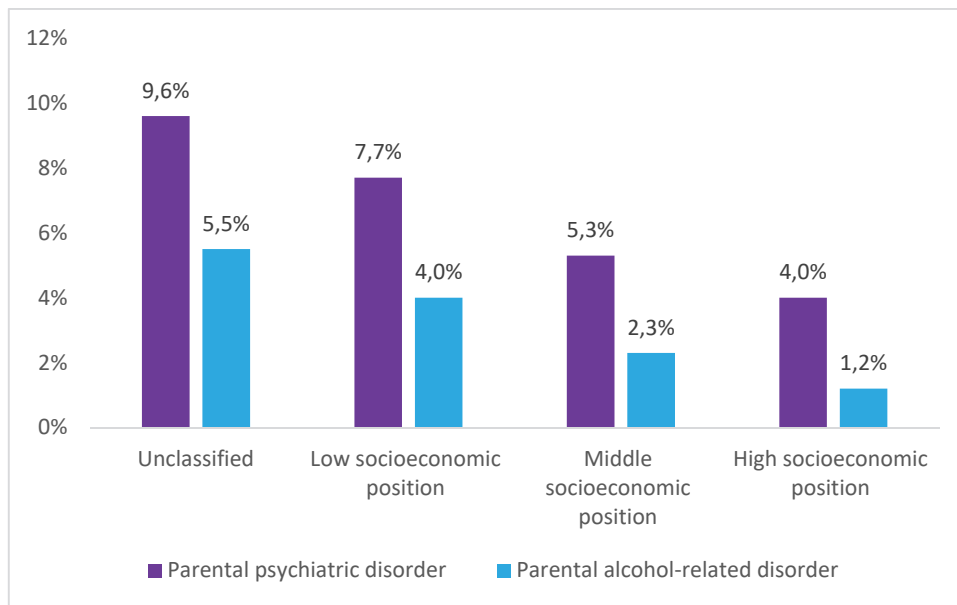
Among children born in 1987–1989, 7.8 % had a parent who was admitted to hospital at least once before the child had reached the age of 18 due to a mental illness and/or substance abuse. Mental illness was the most common reason for hospital treatment among parents: 5.7 % of the children experienced a parent's hospital admission with a psychiatric diagnosis, 2.5 % had a parent who was admitted with a diagnosis related to alcohol abuse, and 1.5 % had a parent who was admitted with a diagnosis related to illicit drug use. The number of parents who had problems with alcohol or drugs to a milder degree was considerably higher. When information was added to hospitalization data on outpatient care related to alcohol or illicit drug use and court convictions on drunk driving and drug offenses, 17.0 % of children were affected. Mental health problems not severe enough to lead to hospitalizations are also relatively common among parents. Survey data from 2007–2011 demonstrated that 18.1 % of parents to children aged 10–18 reported that they suffered from nervousness, anxiety or worry. During a single average year in the period 2006–2008, 10.7 % of mothers and 5.5 % of fathers of children aged 1–18 used an antidepressant.

Among children born in 1987–1989, 12.6 % experienced, at least once before they turned 18, a parent suffering from a physical illness that was severe enough to cause at least one week of inpatient hospital care. In survey data from 2007–2011, 28.4 % of parents to children aged 10–18 reported that they suffered from at least one chronic disease.

A total of 3.4 % of all children born in 1973–1989 experienced the death of a parent before their 18<sup>th</sup> birthday. One third of the deaths among fathers and one fifth of the deaths among mothers were caused by suicides, accidents or violence. For 22 % of the deaths among fathers and 12 % of the deaths among mothers there were indications of alcohol and/or drug use. Parental death caused by suicides, violence or accidents more often affects preschool children, while other types of death among parents primarily affect teenagers.

Addiction and mental illness often contribute to separation or divorce. One consequence of this is that many parents who are admitted to hospital because of these problems do not live with their children, and the parent who lives with the child is often single. About a third of fathers who were admitted to hospital because of substance abuse lived with their children, and about twice as many mothers.

Substance abuse, illness and death among parents mainly affect children who are in a vulnerable social position in Swedish society. It is about three times more common for parents in families with a low socioeconomic position to be hospitalized due to a psychiatric or alcohol/drug-related disorder compared to parents in families with a high socioeconomic position. There is also a social gradient for parental death that is greater for paternal compared with maternal death, and for death due to suicides, violence or accidents.



*Figure 1. Parents' hospitalizations due to psychiatric disorders and alcohol-related disorders, according to family socioeconomic position*

Parents born outside Europe were less frequently admitted to hospital for alcohol or illicit drug use compared with parents of Swedish origin, but they were admitted to hospital slightly more often due to mental illness. Parents with Nordic origins other than Swedish had a higher mortality rate and were more frequently hospitalized for substance abuse and mental illness compared with parents of Swedish or non-Nordic origin.

Parental substance abuse and mental illness are common reasons why children are placed in societal care in Sweden. Among children who spent more than five years in care, 61 % had at least one parent who had been admitted to hospital due to substance abuse or mental illness, and 23 % had a parent who died before the child's 18<sup>th</sup> birthday.

The high number of children affected by a parent's mental or physical illness, substance abuse, or death stresses the importance of a discussion concerning prioritizations and interventions with a varying degree of intensity that can be matched to children with different levels of need.

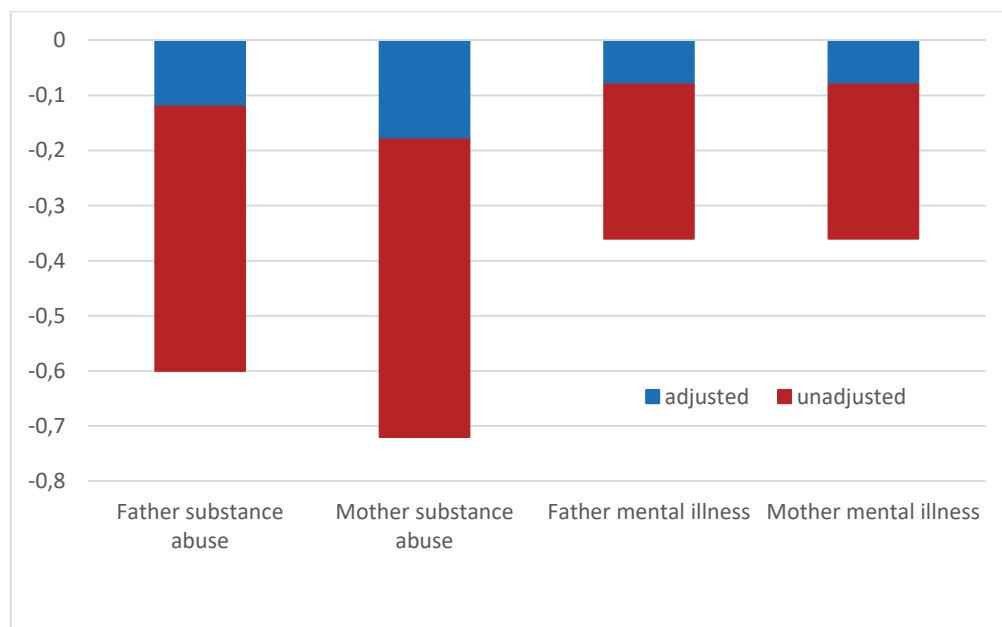


This requires close collaboration between health care and social services and is particularly important in order to develop interventions that are appropriate for children who are next of kin and placed in societal care.

## Children as next of kin and school performance

In this report, the school performance of 655 000 Swedish children aged 15–16 during the years 2003–2008 was analysed. Mean grades and eligibility for secondary school regarding children aged 0–15 with experience of a parent’s death or hospital admission (due to mental or physical illness, or alcohol or illicit drug use) were analysed in comparison with children without these experiences.

Among boys, 27–30 % with experience of parental alcohol or illicit drug use, and 22–23 % with experience of parental mental illness, did not reach eligibility for secondary education. The numbers of girls who reached secondary school eligibility was somewhat higher, but the pattern in relation to parental substance abuse and mental illness was the same in girls and boys. The corresponding numbers among their population peers were 12.3 % among boys and 9.6 % among girls. Mean grades were 0.70 SD lower for children of mothers with a substance abuse problem, 0.60 SD lower among children of fathers with a substance abuse problem and 0.35 SD lower for children of parents with a mental illness.



*Figure 2. Average difference in standard deviations of mean grades. The unadjusted values show the differences when only sex and year of birth are kept constant and the adjusted values are additionally adjusted for parental education, family income support and family composition.*

As much as 85 % of the increased risk of not reaching secondary school eligibility for children of parents with substance abuse issues, and 75 % of the increased risk for children of parents with mental illness, was associated with three social factors: whether the family had received social welfare (i.e. economic assistance), low parental educational level, and parental separation/ divorce. Parental educational background was consistently more important for the child's school performance than parental illness or death. Furthermore, children in families receiving social welfare had generally lower grades, regardless of parental substance abuse and mental illness. The analyses indicate that these factors may contribute to the emergence of substance abuse/mental illness (educational level), but it can also be a consequence (social welfare, parental separation/divorce) of these parental factors.

There were small differences between children of separated/divorced parents and children in families where a parent had died. Compared to children living with both biological parents, about twice as many of these children did not reach eligibility for secondary school. Social factors (e.g. parental education and social welfare) contributed to some extent to these differences in school performance.

Physical illness in parents was exemplified by inflammatory bowel disease, multiple sclerosis and leukaemia. Children whose mothers had inflammatory bowel disease or multiple sclerosis had slightly lower than average grade points (adjusted for the healthy parent's educational background), but there was no adverse effect of physical illness in fathers. School performance was notably poorer among children of parents who died from leukaemia compared to other children in the study population, while no differences from the population mean were seen for children of parents who survived leukaemia.

Overall, the results show that parents' substance abuse, illness and death negatively affect school performance in their children, and that social factors are important contributing factors. Professional groups that meet these children should consider that help with schoolwork could be an important component of psychosocial support for these children. As for preventive interventions in schools, the report points primarily to the need for general interventions for children who do not receive support for schoolwork at home, whatever the reason. This means it applies to children who are next of kin, as well as children with separated/divorced parents or parents with low educational levels.

The results also point to the particularly poor school performance of children where parents' illness and death affect families in contact with social services, either in the form of social welfare reciprocity or through placements in societal care. Consequently, social services is a natural platform for interventions to support the school performance of children in families with social vulnerability, including parental illness and death. Swedish and international research suggest that it is realistic to expect positive results from this type of intervention.

## Health and social living conditions in young adults with experience of childhood parental death

In this report, the health and social situation of 535 000 young adults (18–35 years), born in Sweden during 1973–1978, were analysed using national register data. The report is based on comparisons between individuals with experience of childhood parental death, individuals with experience of parental separation/divorce, and individuals growing up with both parents.

Childhood parental death was experienced by 4.1 % of the study population. Children of parents who died from suicides, accidents or violence (1.7 %) had a two- to three-fold increased risk of dying during follow-up (between age 18–35) compared with individuals who grew up with both their parents. The risk of dying for children to parents who died from other causes increased by 60 %. These deaths were mainly caused by suicides, accidents and violence, or were related to alcohol or illicit drug use, and thus preventable. Among bereaved children, it was twice as common compared with the rest of the population to receive some form of financial compensation from society for a chronic illness and/or disability between the ages 30–35 (about 10 % of the women and 6–8 % of the men). Parental death from accidents, suicides or violence was strongly associated with offspring's mental illness in adulthood; among women with these experiences, 17–18 % had received specialized care with a psychiatric diagnosis during follow-up (14 % among men), which is more than twice as many as among individuals who grew up with both their parents. The risk was particularly high, three to four times higher, in relation to suicide attempts and inpatient hospital care with a psychiatric diagnosis. Hospital admissions for alcohol and/or illicit drug use were five times more common among individuals with childhood experience of a parent's violent death (6–7 % among men and 4–5 % among women) compared to individuals without these experiences during childhood. Parental death from other causes was also associated with a significantly increased risk of hospitalizations for substance abuse or psychiatric disorders.

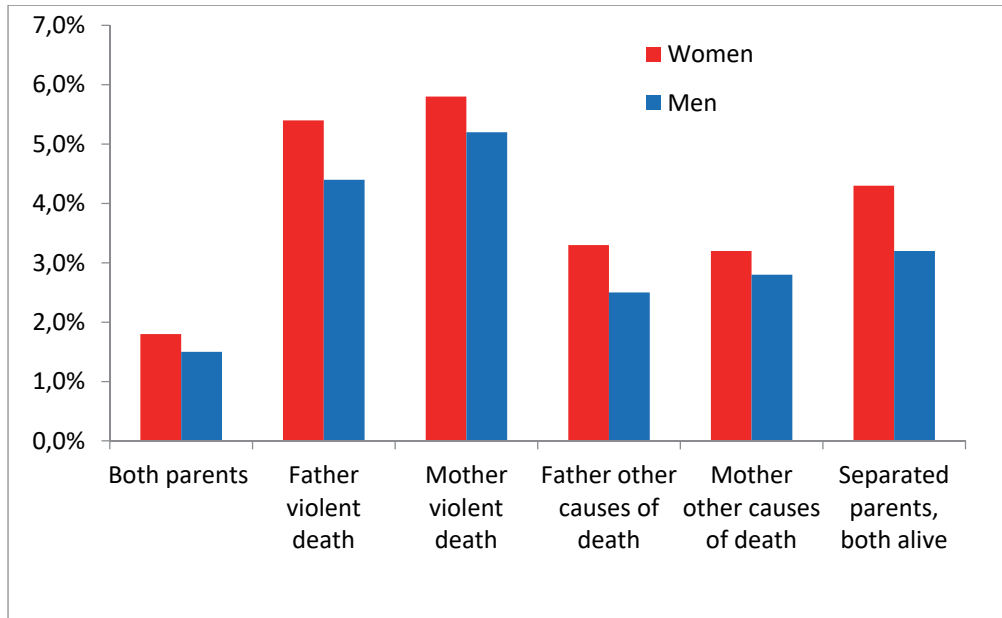


Figure 3. Hospitalizations because of suicide attempts from age 18

Maternal death from an accident, suicide or violence, before the child had reach school age, was associated with a particularly high risk of mental illness and death in young adulthood, in particular for girls. For paternal and maternal death from other causes, the child's age at the time of death was of secondary importance.

Having been convicted of a crime was common among men whose parents had died from a violent cause, about 20 % compared with 10 % in the whole population. Among children of parents who died from other causes, it was 13–15 %. This difference was even greater for serious crime, defined as crimes for which the individual was sentenced to probation, forensic psychiatric care or prison. It was four to five times more common to have been convicted of a serious crime if the parent had died from violent causes, and two to three times more common if the parent had died from other causes. Even though it was far less common for women to be prosecuted compared with men, corresponding risks for women were, in relative terms, still somewhat higher.

To have completed a post-secondary education at follow-up was less common among children of parents who died or who were separated/divorced (25–35 %). Fewer of these individuals worked (the proportion was 6–7 percent lower), and they had lower incomes and a higher reliance on income support compared with individuals who grew up with both parents. Among those in the study population who had become parents, men with experience of a parent's death more often lived without their children and women with this experience more often lived alone with their children, compared with others in the population.

Underlying social factors, such as parental educational level and country of birth only marginally explained the increased morbidity and mortality in children with deceased parents, which was explained more in relation to educational career and income. Parental educational background contributed to health outcomes by adding to the risk associated with the parent's death, so that the risk of negative outcomes was always greater for children of parents with lower education.

These results suggest that children who lose their parents to death from suicides, accidents and violence should be given priority in prevention interventions after parental loss, and that girls who lose their mother during pre-school years are particularly vulnerable. A considerable share of the negative impact in adulthood of parental death is associated with parental risk factors that most likely often precede death, such as substance abuse and mental illness. Therefore, this report highlights the need for preventive measures for this group of individuals, regardless of whether the parent dies because of these problems.

Among children of deceased parents, individuals with experience of societal care were identified as a high-risk group, with high levels of mortality, mental illness, substance abuse, criminality, recipiency of social welfare benefits and a low share of individuals working. Therefore, child welfare services is an important starting point for efforts to prevent illness and social problems in these children when adults. These children should be given high priority and have high availability to child and adolescent psychiatry. Methods to effectively identify and treat mental illness – in the specific context of societal care – need to be developed.

## Health and social living conditions in young adults with childhood experience of parental substance abuse and mental illness

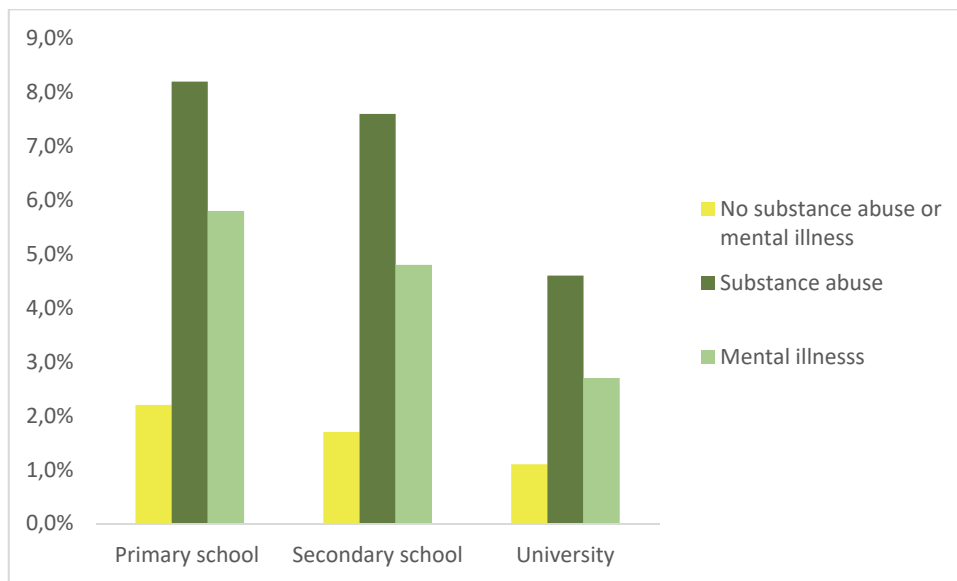
This report consists of an analysis of the health and social situation of young adults with childhood experience of a parent's hospital admission due to a diagnosis indicating alcohol or illicit drug use or a psychiatric disorder. In total, 535 000 children born in Sweden in 1973–1978 were followed until age 30–35. During follow-up, there were 537 deaths among individuals with these childhood experiences. Compared to individuals from the rest of the population, mortality was almost three-fold higher for children with experience of parental substance abuse and twice as high for children with experience of parental mental illness. Analyses of the underlying causes of death showed that this increased risk was associated primarily with violent deaths (suicides, accidents and violence) and related to alcohol and/or drug use.

Among these individuals, it was two to three times more common, compared with the rest of the population, to receive some form of financial compensation from society because of chronic illness and/or disability between ages 30–35 (9–11 % of the women and 6–8 % of the men). After age 18, 20–25 % of women and 15–20 % of men with these adverse childhood experiences had received psychiatric specialist care, either as in- or outpatients, which was two to three times more common compared with the rest of the population. The risk of being admitted to hospital due to a suicide attempt was three times higher. Substance abuse was four- to seven times more common in children of parents with substance abuse (10–12 % among men and 6–7 % among women) and twice as common in children of parents with mental illness.

Individuals with childhood experience of parental substance abuse finished a post-secondary education less often compared to other individuals with comparable grades. Educational careers, after basic education, among children of parents with mental illness was more similar to the rest of the population. The majority of the individuals with these childhood experiences worked and supported themselves by age 30–35, but the proportion of individuals not in the workforce was 7–13 % higher compared with the rest of the population. Having received social welfare benefits in the form of economic assistance was twice as common in children of mentally ill parents and four times more common in children to parents with a substance abuse problem. Differences with regard to disposable income were small. There were no differences between the groups with regard to how many individuals had become parents. However, more than 20 % among those women with childhood experiences of parental substance abuse and/or mental illness who had children lived alone with the children, which is about twice as many as in the rest of the population. Fathers with these childhood experiences more often lived without their children, compared to fathers in the rest of the population.

Alcohol abuse in mothers was associated with more ill health in adulthood for their children compared to alcohol abuse in fathers, while differences with regard to illicit drug use and mental

illness in mothers compared with fathers were small. In relative terms, there were no notable differences in the health between men and women with these adverse childhood experiences in relation to the rest of the study population. Underlying social factors, such as parental educational level and country of birth, only marginally explained the increased morbidity, which was more importantly related to educational career and income. Parental educational background also contributed to health outcomes by adding the risk associated with substance abuse and mental illness, so that the risk of negative outcomes was always greater for children of parents with lower educational levels. People with these childhood experiences, with an origin in the Nordic countries outside Sweden, had a particularly high risk for mental illness and addiction.



*Figure 4. Hospital in- and/or outpatient care related to substance abuse, in relation to parent's highest education*

Individuals who grew up with substance abuse and/or mental illness in the family, and who also had experience of societal care, were identified as an extreme high-risk group. These had high levels of mortality, mental illness, substance abuse, criminality, and reciprocity of social welfare benefits, while occupying a low share of individuals in the workforce. Therefore, child welfare services is an important starting point for the prevention of illness and social problems in individuals with these experiences. The very high occurrence of mental illness has most likely often been evident already during childhood and adolescence. These children must be identified by those who care for their parents and be provided with several forms of support. They need high priority and availability to child and adolescent psychiatry. Methods to effectively identify and treat mental health problems in the specific context of societal care need to be developed and disseminated in Swedish municipalities.



Individuals from families with substance abuse (with no contact with social services) had increased risks for substance abuse, criminality, and social welfare dependency, in addition to the increased risk of psychiatric morbidity seen both among children with experience of parental substance abuse and among children of mentally ill parents. Therefore, preventive interventions emanating from addiction care centres for adults seem particularly urgent.

## How many children in Sweden experience parental cancer and what are the consequences in a life course perspective?

The aim of this report was to describe, using national register data, how common it is for parents in Sweden to be diagnosed with cancer and analyse the impact on school performance and the consequences for the health and social situation in young adulthood for their children. During the years 2007–2012, a yearly average of 6 900 (3.7/1 000) children aged 0–18 experienced that a parent was diagnosed with cancer. Among the 342 522 children who were born in 1990–1992 and followed until their 18th birthday, 5.6 % experienced a parent being diagnosed with cancer and 1.1 % had a parent die from the disease. Having "severe" cancer, i.e. having been treated in hospital for a longer period of time (more than a month), or having died of cancer, was more common among fathers, affecting 37 % of the fathers diagnosed with cancer compared with 25 % of the mothers.

The risk of developing several types of cancer increases with increased age. This means that parents with cancer more often than other parents have a higher educational level, since a longer education, on average, implies that parenthood is postponed to higher ages. This applies, in particular, to cancer in mothers since breast cancer, which is the most common form of cancer in women, more often affects highly educated women. In the case of parental cancer death, the risk is, on the other hand, higher among less educated parents. The family's disposable income was negatively affected by cancer in a parent, in particular if the father fell ill. The reduction in income was especially high if the parent died, but a long hospital stay also led to lower income. In families with non-European origin, it was more unusual for both mothers and fathers to be diagnosed with cancer, compared with parents in families with Swedish origin, whereas there was no difference between parents of different origin with regard to the risk of parental cancer death. The risk of being diagnosed with cancer was lower for parents in rural municipalities compared with parents in metropolitan municipalities, while the risk of dying from cancer was the same in rural and urban municipalities.

This report demonstrates that there are negative preventable consequences – in terms of poorer school performance and increased risk for substance abuse, mental ill-health and criminality – for that one third of children whose parents are diagnosed with cancer so severe it leads to death or treatment in hospital for more than 30 days. For the other two-thirds of these children, no long-term negative consequences, apart from an increased risk of being diagnosed with cancer, were identified.

The analyses of the impact on school performance at age 16 included 1,048,904 children born in Sweden in 1987–1996. The results showed that not having reached eligibility for secondary education was more common if a parent had died of cancer, 39 % more common for a maternal

cancer death and 43 % more common for a paternal cancer death, after the analyses were adjusted for family social background. Not having achieved secondary school eligibility was also more common among children of fathers who survived cancer were treated for a long time in hospital. Children of parents who were treated for a long time in the hospital or who died of cancer had grades that were slightly lower than average (-0.05 – -0.21 SD), after the analysis was adjusted for the family's social background.

Long-term consequences for the health and social situation of children whose parents were diagnosed with cancer during their childhood were analysed in 871 397 children born in Sweden between 1973–1982. Even though children of parents diagnosed with cancer had a higher risk of not achieving secondary education eligibility, they worked to the same degree and had incomes at the same level as their peers at follow-up (at 30–40 years of age). The severity of the parent's illness did not affect these outcomes. Increased risks of substance abuse and criminality, with a risk increase in the order of 25–33 % for men and slightly lower levels for women, were seen in children of parents with severe cancer. A risk increase of 10–27 % for psychiatric care consumption was also noted, but there was no increase in psychotropic drug use. Cancer in a parent, regardless of the severity of the disease, increased the individual's risk of dying from cancer. The increase in risk from age 18 to 30–40 years was 62 % if a parent was diagnosed with cancer and 69 % if the parent died from cancer. The relative impact of a parent's cancer was similar for men and women, apart from an increased risk of hospitalization for attempted suicide/self-harm that was observed only in women, and an increased risk to receive income support at 30–40 years of age that was observed only for men. The results do not indicate any substantial effect of the family's social background on the consequences of a parent's severe cancer for the child's education, work, psychiatric care consumption, substance abuse or criminality.

The results indicate that school is an important arena for preventive measures. Poor school performance and not having achieved eligibility for secondary school were important consequences of a parent's severe cancer. Previous studies have demonstrated that these are significant risk factors for substance abuse and criminality. This study highlights the importance of providing enhanced learning support in school for children of parents who are ill and unable to provide this assistance in the home, temporarily or in the longer term. The lower disposable income in families affected by severe parental cancer indicates that support for these families could also include changes in the health insurance system to improve cancer patients' material resources.

An important finding from this study is that the consequences of a parent's cancer is strongly associated with the severity of the disease. Such differences in impact between severe and milder forms of cancer could possibly be generalizable to other physical illnesses. This indicates that resources to support intervention for children with parents who have physical illnesses should be prioritized for those who have severe chronic illnesses, while the children's own network usually seems to provide adequate support when parents suffer from more temporary illnesses, even if they are potentially life threatening.

A mother's death from cancer increased the probability of a placement in societal care for the child. 9 % of these children (4 % if a father died of cancer) were placed in societal care, compared 3.5 % in the rest of the study population. These children also stayed in care for a longer period

of time compared to other children. A mother's death from cancer increased the risk of severe criminality and substance abuse more than a father's death. This indicates that support from society is particularly important when mothers in socially vulnerable families are diagnosed with cancer, and that Swedish society is already investing significant resources in these children.

## Traumatic stress in refugee parents and consequences for their children

In the previous reports, the general difficulties of children whose parents suffer from mental illness were described. Post-traumatic stress related to experiences of war and torture is a specific form of mental illness that is more common among refugees than in the rest of the population. This report consists mainly of a systematic literature review of empirical studies on post-traumatic stress in refugee parents in exile in high-income countries and the implications for the health and well-being of their children. The report also provides a brief review of important studies on post-traumatic stress and parenting in other situations.

The literature search resulted in 6124 articles, and after careful review of abstracts according to the criteria of the literature review, 38 articles were examined. Of these articles, seven studies (presented in eight articles) met the review criteria. Five studies were cross-sectional and based on relatively small study populations consisting of patients at treatment centres for refugees with post-traumatic stress in the Netherlands, Stockholm, Copenhagen and the United States. In two population-based studies, refugee families from Vietnam 23 years after arrival in Norway, and refugees from the Khmer Rouge in Kampuchea in the United States, were described.

In the reviewed studies, children of refugee parents with post-traumatic stress disorder (PTSD) had consistently higher levels of self- or parent-reported mental health problems (mainly introspective symptoms such as anxiety, depression and PTSD-diagnosis), compared with children of refugee parents without PTSD. This applied to pre-school children, children in the early school-age years, as well as teenagers. This pattern was similar to that previously described in children of Holocaust survivors, where an increase in mental illness in these children was noted only if the parents had been in psychiatric care.

Five studies described different aspects of aberrant interaction between children and parents in families where one or both parents had a PTSD diagnosis. In two Dutch studies of preschoolers, it was found that refugee mothers with PTSD symptoms on average were less sensitive to the child's signals and more dismissive when the child sought contact, compared with refugee mothers without PTSD diagnosis. It was also found that preschool children of parents with PTSD often had unsecure and/or disorganized attachment patterns. In relation to other studies, it was noted that ambivalent attachment patterns were considerably more common in the group of refugees. In a Danish study of children aged 4–9 years, an association between higher levels of PTSD symptoms in children of refugee patients and an insecure attachment was noted. Communication patterns in families were also investigated, and an association between parents who had an "unfiltered" way to communicate about their experiences and an insecure attachment in their children was found. In an American study of teenagers from Kampuchea, a recurring pattern was described where girls with mothers suffering from PTSD took on adult responsibilities in families early.

None of the studies have analysed parental PTSD-problems in relation to children's school performance or social adjustment. The two studies that described consequences for children's development/IQ diverge in their conclusions, and the importance of the families' socio-economic context, as well as the importance of the gender of the affected parent for children's mental health, are insufficiently described in the literature.

The generalizability of this literature review is limited since only two of the studies are population-based; all studies except one have a high or undocumented non-response and the implications of this are not analysed.

These results indicate that consequences for children of parents with PTSD are in many ways similar to consequences of other serious psychiatric disorders in parents. Treatment centres for refugees with war and torture trauma should also have a strategy to acknowledge the children of the parents they treat. Models for this have been developed, including in Sweden.

PTSD diagnosis in refugee parents is often associated with attachment difficulties, and it is therefore important that child care centres are prepared to handle this problem. However, from this literature review, there is no support to systematically offer preventive interventions to children whose parents were exposed to psychological trauma without developing post-traumatic stress.

This literature review indicates that PTSD-symptoms in refugee parents may have substantial consequences for their children. There are indications that this is even more important during the asylum process, which in itself poses significant psychological distress for refugee families. It is therefore important, also for the children, that existing regulations on asylum seekers' rights to healthcare are interpreted so that asylum seeking parents with PTSD-symptoms are offered treatment.

There are indications that parental PTSD can be a significant obstacle to the family's integration into society. The parents' difficulties may have implications for labour market entry and may limit their possibilities to support children in their adjustment process. Studies that can be used as a basis for specific interventions in the Swedish refugee reception concerning these families were not identified in this review. It is essential that such knowledge be sought in further studies.

## Societal costs in Sweden of adults who have grown up with parents with mental illness, addiction to alcohol or drugs

Children and young people living in homes with substance abuse and/or serious illness entails direct and indirect costs to society in the short and long term. This health economic study is an estimate of the society's annual cost to the proportion of people who grew up as a child as next of kin (CNK) to a parent with mental illness or addiction to alcohol/ drugs. The study focuses on society's long-term additional costs that can be attributed to the difference in mental illness and addiction in the CNK-group and the general population in adulthood. The study was conducted by the eHealth Institute at Linnaeus University in collaboration with the Swedish Family Care Competence Centre (Nka) on behalf of the National Board of Health and Welfare Sweden.

The health economic calculations were carried out with a "cost-of-illness" method and included direct and indirect costs to society sectors (state, county councils, municipalities, private sector and individual).

The calculation of the number of children who are relatives of parents with mental illness or substance abuse was based on a register-based long-term follow-up of all children born in Sweden during the six years 1973-1978 and were still registered in Sweden in the year they turned 18. The data is anonymized data from national registries that allow comparison of the CNK-group and the general population in adulthood during the years 1991-2008. Costs are based on the Swedish cost data for the years 2008 and 2009, and recalculated to 2014 prices.

Approximately eight percent of the adult population is estimated to have grown up as relatives of parents who have been treated for mental illness or addiction to alcohol or drugs. In adulthood it is estimated that the group themselves account for about a quarter of society's annual costs of mental illness and addiction to alcohol and / or drugs. The greatest annual societal cost of this group is mental illness for (30 billion SEK), followed by alcohol abuse (16 billion SEK) and drug abuse (9 billion SEK). Most of the costs to society is comprised of so-called indirect costs in terms of lost production during sick leave, early retirement and premature death.

Society's major long-term costs for children who have grown up with a parent with mental illness or addiction is largely due to the fact that the proportion of those with mental illness is twice as high in this group as in the rest of the population, and the proportion with abuse of alcohol and drugs is four to five times as high as the general population. Various preventive measures during childhood targeting the assumed category of CNK in in the long run are able to provide society with significant savings. In a hypothetical situation where CNK in adulthood have the same prevalence of mental illness and addictions as the general population, then the estimated society's total cost is 37 billion SEK (4 billion euro) less per year.

Systematic monitoring and additional health economic studies should be carried out to evaluate the preventive interventions that are effective in limiting CNK of parents with mental illness

and addictions from developing addictions themselves and reduce the need for care for mental illness or addiction.



## The societal cost of fetal alcohol syndrome (FAS) in Sweden

Fetal alcohol syndrome (FAS) is caused by maternal alcohol consumption during pregnancy. Alcohol can have devastating effects on the developing embryo and the brain is particularly vulnerable to prenatal alcohol exposure. The true prevalence of FAS is not known, however, estimates between 0.2 and 9 percent have been reported internationally and 0.2–0.3 percent in Sweden.

Children with FAS often have primary disabilities such as poor adaptive functioning, language deficits, attention difficulties and reasoning and memory deficits. Secondary disabilities that arise after birth as a result of the primary disabilities include psychiatric disorders, disrupted school and employment experiences, alcohol abuse/illicit drug use and trouble with the law. Individuals with FAS often have problems managing daily life and the adverse effects often persist during their lifetime.

The aim of this study was to perform a health economic calculation of the annual societal cost of FAS in Sweden, focusing on the secondary disabilities thought to be feasible to limit via early interventions. The calculations were performed as a cost-of-illness analysis including costs of societal support, special education, psychiatric disorder, alcohol/drug abuse, reduced working capacity and informal caring.

The annual total societal cost of FAS year 2014 was estimated at 700 000 SEK per child (0–17 years) and about one million SEK per adult (18–74 years), corresponding to 14.4 billion SEK per year in the Swedish population using a prevalence of FAS of 0.2 percent. The annual additional cost of FAS, that is the difference between the FAS group and a comparable population, was estimated at 12.6 billion SEK using a prevalence of 0.2 percent.

In conclusion, the cost burden of FAS on the society is vast and the majority of these costs relate to different types of societal support during an individual's lifetime. To decrease the societal costs of FAS both preventive interventions, to minimize the risk of prenatal alcohol damage to arise, and targeted interventions to children with FAS, should be prioritized. That is, the cost of early interventions such as placement of children with FAS in family homes or other forms of housing as well as special education, represent unavoidable costs. However, these type of interventions are highly important to improve the individual's quality of life and future prospects, and also to limit the societal costs as well as the personal suffering in the long-term perspective. There are many unanswered questions and further research is necessary.



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# Children as next of kin in Sweden

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